



## Transplant Program

# Pediatric Allogeneic Transplant Manual



# Table of Contents

|                                                     |           |
|-----------------------------------------------------|-----------|
| <b>IMPORTANT PHONE NUMBERS .....</b>                | <b>2</b>  |
| <b>CHAPTER 1 – WELCOME .....</b>                    | <b>5</b>  |
| THE STEPS OF ALLOGENEIC TRANSPLANT .....            | 8         |
| PREPARATION .....                                   | 9         |
| CONDITIONING .....                                  | 10        |
| TRANSPLANT .....                                    | 14        |
| BEFORE ENGRAFTMENT .....                            | 16        |
| AFTER ENGRAFTMENT .....                             | 18        |
| GRAFT-VERSUS-HOST DISEASE (GVHD) .....              | 19        |
| TRANSITIONING BACK TO SCCA .....                    | 20        |
| PREVENTING INFECTION .....                          | 21        |
| DEPARTURE .....                                     | 22        |
| YOUR CHILD’S TRANSPLANT TEAM AND RESOURCES .....    | 22        |
| DIAGNOSTIC IMAGING EXAMS .....                      | 29        |
| PARTICIPATING IN RESEARCH .....                     | 36        |
| <b>CHAPTER 2 – FINDING YOUR WAY .....</b>           | <b>39</b> |
| TREATMENT AT SCCA .....                             | 40        |
| INPATIENT TREATMENT .....                           | 42        |
| YOUR CHILD’S DAILY ROUTINE .....                    | 42        |
| VISITOR GUIDELINES .....                            | 44        |
| <b>CHAPTER 3 – MANAGING CARE AT HOME .....</b>      | <b>49</b> |
| SUGGESTIONS FOR COPING WITH CARE AT HOME .....      | 51        |
| OUTLINE OF TYPICAL CAREGIVER RESPONSIBILITIES ..... | 51        |
| TAKING CARE OF THE CAREGIVER .....                  | 52        |
| PATIENT AND CAREGIVER EDUCATION .....               | 53        |
| GUIDELINES FOR PREVENTING INFECTION .....           | 54        |
| ANEMIA .....                                        | 60        |
| ANXIETY .....                                       | 61        |
| BLEEDING .....                                      | 62        |
| BODY IMAGE CHANGES .....                            | 64        |
| BREATHING PROBLEMS .....                            | 66        |
| CHANGE AND UNCERTAINTY .....                        | 67        |
| CONSTIPATION .....                                  | 68        |
| DEHYDRATION .....                                   | 69        |
| DEPRESSION .....                                    | 70        |
| DIARRHEA .....                                      | 71        |
| EXERCISE AND BLOOD VALUE PRECAUTIONS .....          | 72        |
| FALL PREVENTION .....                               | 73        |
| FATIGUE .....                                       | 75        |
| FEVER .....                                         | 77        |
| HAND-FOOT SYNDROME .....                            | 79        |
| MEMORY AND CONCENTRATION .....                      | 81        |
| MUCOSITIS (INFLAMMATION OF MUCOUS MEMBRANES) .....  | 83        |
| NAUSEA AND VOMITING .....                           | 85        |
| PAIN .....                                          | 87        |
| PERIPHERAL NEUROPATHY .....                         | 90        |
| SEXUAL HEALTH .....                                 | 92        |
| SLEEP PROBLEMS .....                                | 95        |
| WHITE BLOOD CELLS .....                             | 96        |
| FOOD SAFETY GUIDELINES .....                        | 97        |
| WATER SAFETY GUIDELINES .....                       | 104       |

|                                                       |            |
|-------------------------------------------------------|------------|
| DIET GUIDELINES FOR IMMUNOSUPPRESSED PATIENTS .....   | 106        |
| MORE NUTRITION TIPS .....                             | 110        |
| HERBAL AND NUTRIENT SUPPLEMENTS.....                  | 117        |
| CENTRAL LINE CARE .....                               | 120        |
| OVERVIEW OF MEDICATIONS .....                         | 131        |
| <b>CHAPTER 4 – LONG TERM RECOVERY .....</b>           | <b>141</b> |
| HOW TO TAKE CARE OF YOUR CHILD IN THE FIRST YEAR..... | 143        |
| COMMON CHANGES .....                                  | 146        |
| IMMUNE SYSTEM RECOVERY .....                          | 148        |
| IMMUNIZATIONS.....                                    | 150        |
| GRAFT-VERSUS-HOST DISEASE (GVHD).....                 | 151        |
| MEDICATIONS .....                                     | 153        |
| SECONDARY CANCERS .....                               | 154        |
| RECONNECTING WITH LIFE AND SURVIVORSHIP .....         | 155        |
| SAMPLE LETTER FOR RETURNING HOME .....                | 158        |
| SURVIVORSHIP RESOURCES AND WEBSITES .....             | 159        |
| COMMON INFECTION CONTROL QUESTIONS.....               | 162        |
| <b>CHAPTER 5 – APPENDIX.....</b>                      | <b>165</b> |
| OVERVIEW .....                                        | 167        |
| MAPS AND DIRECTIONS .....                             | 170        |
| CHARTS AND RECORDS .....                              | 173        |

# Important phone numbers

## Seattle Cancer Care Alliance (SCCA)

|                                                                                    |                                                                                                 |
|------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| <b>Seattle Cancer Care Alliance (SCCA)</b><br>6 <sup>th</sup> floor reception desk | (206) 606-7600<br>Mon to Fri, 8 am to 10 pm;<br>Sat to Sun, 8 am 6 pm<br>Holidays, 8 am to 5 pm |
| <b>Seattle Children's Hospital</b>                                                 | (206) 987-2032, after-hours                                                                     |
| <b>In the unlikely event of an SCCA phone outage</b>                               | (206) 467-8762                                                                                  |
| <b>Child Life</b>                                                                  | (206) 606-7621                                                                                  |
| <b>Health Information Management/<br/>Release of Information</b>                   | (206) 606-1114                                                                                  |
| <b>Institutional Review Board for Fred Hutch</b>                                   | (206) 667-6567                                                                                  |
| <b>Interpreter Services at SCCA</b>                                                | (206) 606-6419                                                                                  |
| <b>Long Term Follow-Up</b>                                                         | (206) 667-4415                                                                                  |
| <b>Medical Nutrition Therapy Services</b>                                          | (206) 606-1148                                                                                  |
| <b>Patient and Family Resource Center</b>                                          | (206) 606-2082 fax: (206) 606-2105                                                              |
| <b>Patient Financial Services</b>                                                  | (206) 606-1113                                                                                  |
| <b>Patient Relations</b>                                                           | (206) 606-1056                                                                                  |
| <b>Pharmacy</b>                                                                    | (206) 606-6500                                                                                  |
| <b>Physical Therapy</b>                                                            | (206) 606-6373                                                                                  |
| <b>Radiation Oncology</b>                                                          | (206) 606-7318                                                                                  |
| <b>Receptionist 1<sup>st</sup> Floor</b>                                           | (206) 606-1000                                                                                  |
| <b>Social Work Office</b>                                                          | (206) 606-1076                                                                                  |
| <b>Transition Services</b>                                                         | (206) 606-2125                                                                                  |
| <b>Security (lost and found)</b>                                                   | (206) 606-1111                                                                                  |
| <b>Spiritual Health at SCCA</b>                                                    | (206) 606-1099                                                                                  |
| <b>Volunteer Services</b>                                                          | (206) 606-1075                                                                                  |

## Seattle Children's

|                                                     |                                                                                                                                                                                                                                                   |
|-----------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Seattle Children's Hospital</b>                  | (206) 987-2032, after-hours                                                                                                                                                                                                                       |
| <b>Children's General Council</b>                   | (206) 987-2044                                                                                                                                                                                                                                    |
| <b>Contacting the Unit at Seattle Children's</b>    | (206) 987-2032 voice; (206) 987-2280 TTY;<br>1 (866) 987-2000 to make an appointment<br>or speak to a clinician                                                                                                                                   |
| <b>Family Resource Center at Seattle Children's</b> | (206) 987-2201                                                                                                                                                                                                                                    |
| <b>Getting to Seattle Children's Hospital</b>       | (206) 987-2226                                                                                                                                                                                                                                    |
| <b>Institutional Review Board</b>                   | (206) 987-7804                                                                                                                                                                                                                                    |
| <b>Interpreters</b>                                 | 206) 987-5010 voice or (206) 987-5063 TTY<br>Interpreter services are offered for deaf,<br>hard of hearing, or non-English speaking<br>families. Request these services from your<br>child's nurse or doctor, or call the number<br>listed above. |
| <b>Spiritual Health at Seattle Children's</b>       | (206) 987-2273                                                                                                                                                                                                                                    |

## University of Washington Medical Center (UWMC)

|                                           |                |
|-------------------------------------------|----------------|
| <b>UWMC Human Subjects</b>                | (206) 543-0098 |
| <b>UWMC Office of Regulatory Guidance</b> | (206) 616-8222 |
| <b>UWMC Pharmacy</b>                      | (206) 598-4363 |

# Chapter 1 – Welcome



## **Welcome to the Blood and Marrow Transplant Program**

Welcome to the Blood and Marrow Transplant Program at Seattle Cancer Care Alliance (SCCA). We're here to support you, your child, and your family throughout your treatment, and we created this manual as one of the first steps in that process. We hope you find it helpful.



# Welcome to the Blood and Marrow Transplant Program

We created this manual for families who have a child or teen going through a blood and marrow transplant. Feel free to share the information within it with your child. Older children and teens may want to read it themselves. We welcome your comments about the manual.

Notes from the editor: First, within the document, you will see references to “you and your child”. The “you” and “your” in these instances refers to the primary caregiver(s) who is typically the child’s parents. Second, instead of using the pronouns “he or she” throughout the document when referring to the child having a transplant, we alternate between “he” and “she.”

## The steps of allogeneic transplant

The cell that is being transplanted is the stem cell, which is made in the bone marrow. Stem cells are immature cells that grow and mature into red blood cells, white blood cells, platelets or plasma cells. Stem cells are an essential part of a person's immune system. Names you will hear include:

- Bone marrow transplant (BMT)
- Marrow transplant
- Peripheral blood stem cell transplant
- Stem cell transplant
- Hemopoietic stem cell transplant

## Type of transplant

There are several types of transplant. You may hear others discussing a process different from yours. Below is a chart reviewing each type. This chapter will then go into detail.

| Type of transplant                | Cell source                         | Goals                                                                                                                                                                                                   |
|-----------------------------------|-------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Allogeneic<br>Related             | Another person<br>Family member     | Deliver highest dose of chemotherapy and radiation to eliminate disease.                                                                                                                                |
| Unrelated                         | Another person<br>Usually anonymous | New cells replace patient's immune system.                                                                                                                                                              |
| Mixed chimerism (mini)<br>Related | Another person<br>Family member     | Deliver moderate dose of chemotherapy and radiation to set up a mixed immune system.                                                                                                                    |
| Unrelated                         | Another person<br>Usually anonymous | New immune system attacks cancer.                                                                                                                                                                       |
| Autologous                        | Patient                             | If patient has cancer:<br>Deliver highest dose of chemotherapy and radiation to eliminate disease.<br>If patient has an autoimmune disease:<br>Halt progression of disease and reset the immune system. |

The transplant process can be divided into steps. Each step has its own purpose and challenges. The steps are:

### Planning ahead

This step begins when you first think about transplant as a treatment option for your child. You start to organize yourself and your family to undertake this journey.

### Preparation

Once you arrive at the clinic, you will begin the process of medical evaluation, orientation, informed consent, and get ready to begin conditioning therapy. Family members prepare to assume the caregiver role.

### Conditioning

High-dose chemotherapy and/or radiotherapy is given to your child.

### Transplant

Stem cells harvested from the bone marrow or collected from the circulating bloodstream are infused.

**Before engraftment**

Your child will receive close monitoring, supportive treatment, and management of complications while waiting for signs that the transplanted stem cells are engrafting (growing and developing).

**After engraftment**

This is the time after the first signs of engraftment when your child's new white cells, red cells, and platelets are being produced and the immune system is starting to recover. Your child will still need close monitoring and supportive treatment.

**Long-term recovery**

Your child will leave the clinic and further care and treatment will be provided by your hometown doctor. The challenges in this stage include managing possible late complications and resuming life at home.

**Preparation**

When you first arrive, you and your child will go to the clinic to begin the pre-transplant evaluation. You will learn the proposed treatment plan, meet with your healthcare team, and get answers to your questions about treatment. You and your family members can attend classes on how to manage symptoms at home and prevent infection. All of this is to prepare you for the next step—conditioning therapy. Childcare is not provided during appointments or classes and should be arranged ahead of time if needed. As a courtesy to the large number of patients with weakened immune systems in the clinic, please refrain from bringing family members or caregivers with even minor infection symptoms (cold or otherwise) into the clinic. Also, please do not bring any animals but service dogs to the clinic.

**First clinic appointments**

Your first visit at the clinic will consist of meeting your primary doctor and your team nurse. Your nurse will take your child's vital signs, draw blood, take a short history, and give you an orientation of the clinic. Your primary doctor will complete a health history and physical examination. You will be given a schedule of visits and consent forms that give permission to conduct the pre-transplant evaluation. In the first few days, you will meet with a social worker who will answer the questions you may have about your housing and social issues, describe resources you may access, and offer support for you and your family members.

**Arrival conference (meeting with the physician and care team members)**

After the health history and physical exam are done, you will be scheduled for a conference. This usually takes place on the 2<sup>nd</sup> day after you arrive at the clinic. Your attending physician will conduct the conference. You may invite members of your family, including the donor, to attend. The attending physician will talk to you about the process of having a bone marrow transplant. He or she will discuss the plan of treatment including the risks and benefits. You will receive a consent packet at your first appointment, please bring it with you to your arrival conference. The age and maturity of the child will determine whether he should attend the conference. We discourage small children from attending. If you would like, you may schedule time with our Child Life specialists for medical play with small children.

**Evaluation and work-up**

The evaluation for transplant includes blood draws for tissue typing and clinical tests, a bone marrow aspiration and possible biopsy, chest X-rays, an electrocardiogram (ECG), pulmonary function tests, and other tests the doctor may order. You will meet with a dietitian and possibly have a dental checkup. When the

results of these tests are available (5 to 7 days) you will be scheduled for placement of a central venous line catheter. Consults and tests occur both at the clinic and at Seattle Children's Hospital. The location and time of appointments will be on your schedule. Schedule changes occur frequently due to testing results.

### **Informed consent conference**

You will be scheduled for a second conference to review your child's test results before proceeding with treatment. The doctor must share information with you so that you will be well informed and able to make the decision to go ahead with your child's transplant. The conference provides you and your family the opportunity to ask questions. After the conference, you (or your child's legal guardian) will be asked to sign consent forms giving permission to proceed with treatment.

You and your family will:

- Receive copies of all protocol consent forms for the protocols in which your child is participating.
- Be offered copies of all protocols for the protocols in which your child is participating.
- Be offered a copy of the dictated "Data Review Conference" summary.

### **Central venous line placement**

Placement of this catheter is done at Seattle Children's Hospital. Your child will receive sedation (medicine to make them sleep) before the surgery begins. Because of this sedation, your child may not eat or drink anything before the catheter is placed. Not eating or drinking prevents the possibility of vomiting during surgery. **Talk to the Pediatric Team regarding these specific instructions.** We will schedule a time for you to return to the SCCA Clinic the following day so that one of the nurses can teach you how to take care of your child's catheter.

## **Conditioning**

Conditioning consists of high-dose chemotherapy with or without total body irradiation. The purpose of conditioning therapy is to remove cancer cells or to remove the remaining immune system, so that new marrow can grow. Conditioning can be received in the clinic or in the hospital. Your care team will discuss your child's treatment plan with you.

### **Chemotherapy**

All chemotherapies and radiation have some effects on normal cells as well as on diseased cells, and unpleasant effects can be expected. Each of the chemotherapy drugs has different effects. The specifics of the chemotherapy prescribed for your child will be explained when your therapy program is planned. Common side effects include nausea, vomiting, diarrhea, dry mouth, fatigue, hair loss, and skin changes. Some of the side effects of chemotherapy happen right away and can be managed with other drugs.

Nausea and vomiting are major concerns for your child. Several drug therapies are available to relieve nausea and keep your child comfortable. Diarrhea can result from chemotherapy and is treated with fluid and electrolyte replacement. Hair loss is temporary, and your child's hair should start growing back a few months after the transplant.

## Safe handling of chemotherapy at home

Because chemotherapy (chemo) is made up of dangerous chemicals that can harm you, it is important to take precautions, especially at home. Only you (the caregiver) should touch chemo and the items used to deliver the chemo, such as syringes and needles. Pregnant women, children, and pets should avoid touching chemo and contaminated waste. In this section, we'll teach you how to handle the medication safely at home.

### Storing your chemo

Below are some tips for storing chemotherapy safely:

- Keep chemo pills in their original container; do not transfer them to a pill box.
- Do not crush or open chemo medication.
- Some medications need to be refrigerated or kept away from light; check medicine labels for special instructions; follow additional instructions from your care team.
- Store chemo and equipment in a safe place and out of reach of children and pets.
- Do not store chemotherapy in your bathroom because humidity may damage the drugs.

### Disposal of chemo

Because chemotherapy is dangerous, it shouldn't be thrown away in your trash. If your child is receiving intravenous (IV) chemo at home, IV equipment and gloves should be put in the hard, plastic containers that come with the chemo supplies. The container should say "Chemotherapy Waste" or something similar.

If the waste is too large to fit in the plastic container, put all sharps in the hard, plastic container. Put the other equipment in a separate, leak-proof plastic bag (such as a garbage bag) and seal it tightly with rubber bands.

The company supplying your child's chemo and equipment will tell you who will remove the waste containers. If your child is taking oral chemotherapy, ask your care team how to dispose of it or refer to *How to Safely Dispose of Prescription Medications and Sharps*.

### Managing chemo spills

The company that supplies your child's IV chemo will include a chemo spill kit with her medicine. If her chemo spills, follow the instructions on the kit and inform your child's care team. If, for some reason, you don't have a spill kit available, follow these steps:

- Put on 2 pairs of disposable gloves.
- Clamp the IV tubing.
- Turn off the pump if you're using one.
- Place the following in a leak-proof plastic bag, such as a garbage bag:
  - All the tubing and containers
  - The pump and the carrying case, if you have one
- Soak up the spill with paper towels.
- Clean the area with soap and water.
- Rinse with clean water.
- Put all the supplies used to clean up the spill in a separate leak-proof plastic bag.
- Remove your gloves and wash your hands with soap and water.
- Call your care team for instructions on how to manage the spilled chemo, the equipment, and the dirty cleaning supplies.

## **Other instructions**

### **Body wastes**

Your child's urine and stool contain chemotherapy while she is receiving treatment, and for up to 2 days after she's finished treatment. Traces of chemotherapy may also be present in vomit, vaginal fluid, and semen. Your child may use the toilet (septic tank or sewer) as usual. For the first 48 hours (2 days) after your child receives chemo, instruct her to flush the toilet twice with the lid closed each time she uses it. Be sure your child washes her hands with soap and water each time she uses the bathroom.

### **Laundry**

Wash her clothing and bedding normally unless they become soiled with chemotherapy. If that happens, put on disposable gloves and handle the laundry carefully to avoid getting chemo on your skin. Soiled items should be washed separately from other clothes. If you don't have a washing machine, place the dirty items in a sealed, leak-proof plastic bag until they can be washed.

### **Skin care**

Chemotherapy can irritate you and your child's skin. If chemo spills on you or your child, thoroughly wash the area with soap and water, and dry it. If irritation develops that lasts more than 1 hour or if a rash develops, call your child's care team. Wear gloves when working with chemo, chemo-soiled equipment, or waste to prevent it from touching your skin.

### **Eye care**

If chemotherapy gets into you or your child's eyes, flush them with water for 10 to 15 minutes, and contact your care team immediately.

## **Questions and answers**

### **Is it safe for family members to have contact with my child during chemotherapy?**

Yes. If your child wishes to, spending time with others is encouraged. Living, eating, and doing activities with others is safe. Hugging and closed-mouth kissing is safe, too.

### **Is it safe for my family to use the same toilet as my child receiving chemo?**

Yes. We understand your family may have concerns, but as long as any chemotherapy waste is cleaned from the toilet, it is safe to share a bathroom.

### **What should my child do if she doesn't have control of her bladder or bowels?**

Use a disposable, plastic-backed pad, adult or pediatric diaper, or sheet to absorb urine or stool. When it gets soiled, put on gloves, remove the soiled piece, remove the gloves, and then wash you and your child's skin with soap and water. If your child has an ostomy, you should wear gloves when emptying or changing the bags. Discard disposable ostomy supplies in the chemotherapy waste container.

### **What if my child uses a bedpan, urinal, or commode?**

If your child is using one of these, it's important for you to wear gloves when emptying and cleaning the containers. You should rinse the container with water after each use and wash it with soap and water at least once a day.

### **What if my child vomits into a basin?**

It's important for you to wear gloves when emptying and cleaning your child's basin. You should rinse the basin with water after each use and wash it with soap and water at least once a day.

### **Is it safe for my child to be sexually active during treatment?**

Please ask your child's care team this question, as this depends on the type of treatment she is on. Because traces of chemotherapy may be present in vaginal fluid or semen for up to 48 hours after treatment, your child may need to take special precautions.

### **Is it safe to throw IV chemotherapy in the trash?**

No. Chemotherapy waste is dangerous and should be thrown away separately. If your child is receiving IV chemotherapy at home, you should have received a special waste container for the chemotherapy and equipment (such as used syringes, needles, tubing, bags, cassettes, and vials). This container should be hard plastic and labeled "Chemotherapy Waste" or something similar.

### **Can we travel with my child's chemotherapy?**

Traveling with chemo is usually fine but check with your child's care team or home infusion supplier to confirm it is OK. Some chemotherapy requires special storage, so you may need to make plans, such as traveling with a cooler. Regardless of how you travel (by plane, car, or another mode of transportation), always seal your chemotherapy drugs in leak-proof plastic bags.

### **Sources**

Chemotherapy and Biotherapy Guidelines and Recommendations for Practice. Fourth Edition, Appendix 1, pages 466-467. Editors Martha Polovich, Mikaela Olsen, and Kristine B. LeFebvre, ONS Publication, 2014. Division Pittsburgh PA

Safe handling and Administration Considerations of Oral Anticancer Agents in the Clinical and Home Setting, *Clinical Journal of Oncology Nursing*, 2012, 16(6), pages 192-197. Joanne Lester, PhD, CRNP, AOCN

Home Safety for Patient Receiving Anti-Cancer Medications, 2016, Oncolink Team, <https://www.oncolink.org/frequently-asked-questions/cancer-resources/brown-bag-chat/caregiver-exposure-to-chemotherapy>

Safe Handling of Chemo at Home, 2018, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4324350>

Safe Handling: Implementing Hazardous Drug Precautions. *Clinical Journal of Oncology Nursing*, 2012, 16(3) pages 251-254. Anne Marie Watson, RN, MPH, OCN, CHES, Susan Mason, RN, MSN, OCN, Michele Busshart, RN, OCN, Angela Spruill, RN, BSN, OCN, Summer Cheek, RN, BSN, OCN, Ashley Lane, RN, OCN, Kathy Sabo, RN, BSN, CPHON, ATC, and Amanda Taylor, RN, BSN, CPHON

## **Total body irradiation (TBI)**

Total body irradiation (TBI) is a type of radiation therapy that utilizes high-energy X-rays for your child's cancer treatment. TBI is radiation given to the entire body. TBI is given according to the treatment plan specific to your child. It can vary from 1 to 3 times a day, 20 to 40 minutes at a time, for a length of 1 to 4 days. The treatment length is dependent on your child's body size and prescribed radiation dosage. However, once determined, the amount of time your child spends in treatment will be the same.

### **What are TBI treatments like?**

TBI treatment will not cause pain or discomfort for your child. He or she will not have any unusual sensations while the radiation machine is on. Your child will not become "radioactive." A family member may accompany your child to the radiation therapy department. However, it is necessary for your child to be alone in the room during treatment. Your child may feel alone during their treatment. Monitors are outside so that the nurse and radiation technician see and hear your child at all times. You will be given detailed instructions when your child's nurse teaches you about the radiation course.

## Side effects of TBI

**Nausea:** Most often occurs 1½ - 2 hours after a dose of TBI. Your child will be started on medication to ease any feelings of nausea. The day before TBI begins, your care team will review the medications your child should take before each TBI treatment.

**Dehydration:** TBI can cause dehydration much like if your child were exposed to the sun for too long. Other side effects such as diarrhea and nausea add to this problem. Your child may receive hydration through an IV during each day of TBI to help prevent dehydration.

**Skin sensitivity:** TBI acts as a heat source even though your child will not feel this right away. You and your child will notice her skin may appear flushed or darker following radiation therapy. Following treatment, your child's skin will be more sensitive, especially to sunlight. You and your child can take precautions to avoid skin burns during treatment. This includes wearing loose fitting clothing, removing all jewelry, glasses, and contacts. The clamp used to hold your child's central catheter will also be removed. The nurse or doctor will assess your child's skin frequently. Your child should avoid using lotion and deodorant before TBI.

**Alopecia:** Temporary hair loss may occur gradually over about two weeks following treatment.

**Parotitis:** The parotid glands are located near and in front of the ears. Parotitis is swelling of the parotid gland, and it can cause headaches, fevers, tiredness, and appetite loss. Parotitis is not a common side effect but has been seen in TBI patients. Symptoms will occur from 4 to 24 hours after TBI. Ice packs and Tylenol® help to relieve the discomfort from the swelling. Parotitis will resolve in 24 to 72 hours following treatment.

**Diarrhea:** Usually develops within the first week following TBI and can be treated with medications.

**Mucositis:** Mucositis is painful swelling or ulceration of the glands that secrete mucous and the fast-growing cells that line the mouth and throat. It can cause dryness, swelling, and a painful mouth and throat. Mucositis is treated with salt-water rinses and pain medication. If pain continues, narcotics will be used.

## Transplant

The transplant takes place a day or two after the chemotherapy and/or radiation treatment has been completed. The goal is to infuse stem cells. Stem cells are cells from which all types of blood cells grow. These cells can be collected from bone marrow, circulating blood, or umbilical cord blood after a baby's birth. Stem cells are infused through your child's central venous line in the same way that any blood transfusion is given. It takes place either in the infusion room at SCCA or in your child's room at Seattle Children's Hospital.

In allogeneic transplants, the cells are harvested from the donor (either from a family member or an unrelated person) on the same day the cells will be given to your child.

### The bone marrow donor

Donors will receive their own educational materials when they arrive at the clinic. The bone marrow donor is the person who makes an allogeneic transplant procedure possible. He or she is the person who most closely matches the genetic type of the patient. The donor may be an immediate family member, often a brother or sister. In some cases, the donor and patient are not related but are still closely matched in tissue type. Most

families arrive knowing who the donor will be. Even with a known donor, it is still important that some typing be repeated. This information assures the medical team that the best possible donor has been selected. There are no age restrictions for donors.

## **Marrow harvesting**

The actual marrow harvesting is performed in surgery where marrow is taken from the hip bones. Marrow is obtained through needles inserted through the skin into the hip bones. Most donors go home from the hospital the same day after marrow harvest unless an overnight stay is medically necessary.

## **The stem cell donor**

Stem cells are produced in the bone marrow and circulate in the bloodstream. The stem cells that circulate in the bloodstream are called peripheral blood stem cells, or PBSC's. Normally, small numbers of stem cells circulate in the bloodstream. In addition to obtaining stem cells by harvesting them from the bone marrow, it is possible to obtain them by collecting them from the bloodstream. However, before that can be done, it is necessary to stimulate the movement of stem cells into the bloodstream. This is called mobilization.

## **Stem cell mobilization**

Mobilization of stem cells is achieved by giving the donor special proteins called growth factors. It takes a few days for the body to respond to the mobilization therapy. When blood tests show that the cell count is high enough, collection can begin. Once in a while, a stem cell donor must undergo more than one cycle of mobilization to collect enough stem cells for transplantation.

## **Collecting stem cells**

Stem cells are collected in the Apheresis Unit. Before beginning collection, the donor must have a catheter (tube) placed into a large vein. The placement of the catheter may take place several days before or right before the collection procedure. The collection of PBSC's takes about three hours. During the procedure, the donor relaxes in a chair or bed and can watch television or read.

The donor's blood is withdrawn through the catheter and circulated through a machine that separates out the stem cells and collects them. The remaining blood cells are returned to the donor via the catheter. The procedure is painless. When the procedure is over, the donor can resume normal activities.

## **Infusion of donated cells**

Marrow or stem cells are infused into your child as soon as the cells are available from the donor. Your child may receive one or more bags of cells. In some cases, the bone marrow is processed before infusion. Based on recommendation of the Transfusion Services Office, if the blood type between your child and his donor does not match, red blood cells may be removed from the marrow before infusion. The nurse attaches IV tubing to the bag of cells and connects the tubing to your child's central catheter line. Each bag of cells is infused one after the other. During the infusion, the nurse will check vital signs (blood pressure, pulse, respiration, and temperature). Your child may be connected to a heart monitor, so nurses can observe their heart rate and rhythm. The length of the infusion depends on the volume, or amount, of stem cells to be given. The infusion takes 30 minutes to 2 hours to complete. Your child may receive stem cells on more than one day because of the donor collection process.

## Before engraftment

Signs that the new stem cells are growing (engrafting) and beginning to produce blood cells are expected from 10 to 28 days after transplant. Often the first sign of engraftment is a rising white blood cell count. Your child will be monitored carefully while waiting for engraftment. The goals are to support your child until they are producing blood cells again, to provide prompt treatment if complications occur, and to prevent infections. You and your child may feel uncertain, stressed, defenseless, and vulnerable while waiting for the engraftment to occur. Some families feel a loss of personal control associated with the daily monitoring, medical procedures, and treatments following your child's transplant. Coping at this time can be a challenge. Keep talking to your child's team about your concerns and concerns your child has.

### Blood counts: what are they and what do they mean?

Blood counts are numbers that show the amount of blood cells circulating in the blood stream. Blood will be drawn from your child's central line to check the counts. The blood counts that are monitored closely are the total number of white blood cells (ANC), the hematocrit, and the platelet count.

| Blood component Name                                                                           | Function                                                                      | Normal ranges                   | Transplant transfusion guidelines                                                                            |
|------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------|---------------------------------|--------------------------------------------------------------------------------------------------------------|
| <b>Hematocrit</b><br>% Red Blood Cells per volume of whole blood<br>Erythrocytes<br>HCT        | Carry oxygen to the body<br>Give color to the skin<br>Give energy to the body | Adult:<br>37 to 52%             | Transfuse:<br>If HCT less than 26%<br>OR<br>If patient symptomatic                                           |
| <b>Platelets</b><br>Thrombocytes<br>PLTS                                                       | Prevent bleeding<br>Help blood to clot                                        | 150,000 to 500,000 / mm3        | Transfuse:<br>If less than 10,000 or, for bleeding or, if otherwise indicated                                |
| <b>White blood cells</b><br>WBC                                                                | Fight infection                                                               | Adult:<br>5,000 to 10,000 / mm3 | Not applicable                                                                                               |
| <b>Absolute neutrophil count</b><br>ANC<br>Neutrophils<br>Polys, bands, segs, and granulocytes | Type of WBC that is first to respond to potentially fatal infections          | Over 1,000                      | Very rare occurrences;<br>Only if life threatening infection is present with no signs of white cell recovery |

### Effects of chemotherapy and radiation on blood counts

The amounts of chemotherapy and radiation used in conditioning cause the bone marrow to stop producing cells for a time. Your child's blood counts will be low during this period, and she may need a blood transfusion. After your child's blood counts are drawn, the doctor will determine your child's transfusion needs. When your child's stem cells begin to engraft, her blood counts should start to rise. The actual time for recovery of cells will vary from person to person.

### Red blood cell transfusions

When your child's red blood count is low, the doctor will order packed red blood cell (RBC) transfusions. This consists of a bag or bags of concentrated red blood cells, each transfused over 2 to 4 hours. This blood has been typed and cross-matched with your child's to minimize the chance of reaction. This means that the RBC

donor and your child have a compatible blood type. It's still possible that your child may have a reaction. Symptoms include fever, chills, hives, itching, and/or breathing problems. If your child has any of these symptoms during transfusion, be sure to report them right away to your nurse.

All blood products are tested for infectious diseases such as hepatitis, HIV/AIDS (human immunodeficiency virus and acquired immunodeficiency virus), and West Nile. If your child is cytomegalovirus (CMV) negative, your child will receive CMV safe blood, also known as leuko-reduced blood products.

## Platelet transfusions

Collection of platelets is done at the Puget Sound Blood Center. Platelet transfusions come from three types of donors:

- **Random pooled platelets:** from two to six volunteer donors in the community, which are pooled in the same bag.
- **Random apheresis platelets (RAP):** From one volunteer donor in the community.
- **Matched apheresis platelets (MAP):** From one HLA matched unrelated donor in the community.

## Infections

Infections remain one of the major complications of transplantation. Your child is at high risk for infections because of low white blood cell counts and a poorly functioning immune system.

All people have different types of bacteria, viruses, and yeast growing on their skin and in their bodies. Many of these organisms are needed for proper functioning of our bodies. The immune system controls the growth of the organisms so that they do not make us sick. The source of infection in many patients is their own organisms. Routine cultures are important because the results keep the doctor informed about the bacteria, viruses, and yeast your child may have growing in their body that may be causing infections. Culture results help doctors to prescribe the right antibiotic when your child has an infection. Your child may have negative culture results, but he may still clinically look and feel like he has an infection.

Another source of infection is organisms from other people. Hand washing plays a key role in stopping the spread of infection from one person to another. It is important that everyone entering and leaving your child's hospital or clinic room washes their hands. This is why visiting between your child and other patients is not allowed in the hospital and why your family members should not go into other patients' hospital rooms.

The medications used to treat infections include antibiotic, antifungal, and antiviral medications. Respiratory viruses, which cause the common cold or the flu in people with normal immune systems, can lead to pneumonia in transplant patients. These viruses include parainfluenza, adenovirus, and respiratory syncytial virus (RSV). If your child develops symptoms of an upper respiratory infection, such as stuffy nose, sore throat, cough, chills, fatigue or fever, we will get a naso-pharyngeal and throat (NPT) culture to determine if there is a specific viral infection. Your child will be in isolation as soon as symptoms develop and remain in isolation until the cultures are negative and your child no longer have symptoms. Family members or friends with cold or flu symptoms should stay away from your child until they are well.

## Cytomegalovirus (CMV)

Cytomegalovirus (CMV) infection is a member of the herpes family and is very common. Between 50 to 80% of the US population have had a CMV virus infection, according to the Centers for Disease Control (CDC). CMV infections are rarely serious in otherwise healthy children and adults and usually cause only mild symptoms, if any.

Once a person has had a CMV infection, the virus usually lies dormant (inactive) in the body but can be “reactivated” and cause serious illness in people who have weakened immune systems due to illness, chemotherapy, or transplant.

All stem cell transplant patients are monitored weekly for reactivation, regardless if they are CMV positive or negative. This is done with a blood test called CMV PCR. In stem cell transplant recipients, the antiviral drug ganciclovir or foscarnet can be given intravenously to treat the reactivation. It will be recommended to continue monitoring for CMV reactivation for one year after transplant. This can be coordinated with the patient’s referring doctor.

### **Sinusoidal obstruction syndrome (SOS)**

Sinusoidal obstructive syndrome is a disease caused by injury to the liver, which involves the partial blockage of blood flow through small veins. Congestion results in post-sinusoidal obstruction and liver damage.

The cause of this problem is the chemotherapy and/or radiation used to prepare your child for transplant. High levels of conditioning therapies are needed for successful transplant. Such intensive therapy can damage otherwise healthy tissues in addition to its desired effects. The liver is especially susceptible. The signs of SOS are fluid retention, weight gain, and an increase in liver function test values.

### **Gastrointestinal (GI) problems**

The chemotherapy and/or radiation used in the high-dose regimen also affect the entire GI tract. These side effects range from mild sore mouth and throat, nausea/vomiting and diarrhea, to more severe forms, which can include inflammation and mucosal breakdown throughout the GI tract. Narcotics are used for pain control, and intravenous nutrition (TPN) is often indicated. These side effects get better with engraftment.

### **Lung problems**

Your child will be monitored closely for signs of any breathing difficulties due to fluid overload, pneumonia, or side effects of chemotherapy or radiation. Daily physical examinations and routine chest X-rays will be done.

### **Skin problems**

The skin is a sensitive organ often prone to some damage from chemo and radiation. These side effects range from a mild redness like a sunburn to red, dry, and peeling skin.

### **Kidney problems**

Kidneys are organs that produce urine, remove bodily waste, and process some drugs out of the body. Some drugs affect kidney function. Your care team keeps a close watch on your kidney function through blood tests, the careful monitoring of the quantity and quality of urine, and frequent measurement of body weight. These and other factors help guide them to prevent and treat kidney problems and help return kidney function to normal.

## **After engraftment**

As your child’s new immune system develops, the goal is to support his recovery and manage any complications that may arise. Your child’s immune system is immature and is still vulnerable to infections.

Your child may need infusions of red blood cells or platelets. Fluids and nutritional support maybe needed until he is eating and drinking enough.

It is common to feel tired during this phase. Even though your child may feel tired, activity is good. Being active helps prevent some complications. Your child may also feel “down” or depressed at times during the recovery period. Your child may grieve because of changes in physical functioning or dependence on others for care or even changes in relationships with your family members. These are all common reactions to the intense experience of having a transplant. Your child may experience decreased concentration at this time. See the sections on Fatigue, Depression, and Memory and Concentration for more information.

Progress may seem slow. You child may feel frustrated because they want to get well rapidly. It just takes time to recover. Former patients tell us that they coped by taking one day at a time. They found that if they set a simple and realistic goal to achieve each day, it was easier for them to see the progress. It is helpful talking with staff about what is a realistic goal.

As your child recovers and no longer needs close monitoring and treatment, the team will help you and your child prepare to leave SCCA and return to the care of your child’s local doctor. Despite the eager anticipation, you and your child may experience separation anxiety as you prepare to leave.

## **Graft-versus-host disease (GVHD)**

### **What is acute graft-versus-host disease (GVHD)?**

GVHD is caused by immune cells from the donor that attack tissues and organs in the patient who has received a transplant. Acute GVHD can occur any time after engraftment, but usually begins within the first three to four weeks after transplant. GVHD is often the major problem after bone marrow, cord blood, or blood stem cell transplantation. It may affect the skin, liver, stomach, and intestines. After transplant, your child will take two or three different medicines that suppress the new immune system to prevent acute GVHD. Despite taking these medicines, two out of three patients with a related donor and four out of five patients with an unrelated donor develop GVHD and need additional treatment.

### **What are the treatments for acute GVHD?**

The usual treatment for GVHD is a steroid called prednisone (taken by mouth as an outpatient) or methylprednisolone (given by IV as an inpatient). The goal of this treatment is to control symptoms of GVHD. The dose is reduced (tapered) over weeks or months depending on your child’s response. We want to limit the number of days that your child takes high-dose steroids to reduce their risk for serious infections and other side effects.

### **What is mild GVHD?**

Mild GVHD does not affect the liver. Mild GVHD occurs in 1 out of 3 patients with a related donor and 1 out of 5 with an unrelated donor. Mild GVHD symptoms include:

- Rash
- Loss of appetite
- Nausea
- Vomiting
- Mild diarrhea

### **What is the treatment for mild GVHD?**

Mild GVHD of the skin may be self-limiting and not require treatment. Alternatively, it may be treated with ultraviolet light called PUVA or topical creams. If it persists, low-dose prednisone may be used. Mild GVHD of the stomach and intestines can also be treated with low-dose prednisone. In this case, doctors might add a special steroid called beclomethasone for the stomach, and another special steroid called budesonide for the intestines. You may hear these called “B&B.” This use of B&B generally allows the doses of prednisone to be tapered more quickly.

### **What are the signs of more than mild GVHD?**

In addition to the symptoms listed under mild GVHD, symptoms might include:

- A more intense, itchy, and inflamed rash
- Large amounts of frequent and sometimes bloody diarrhea
- Abdominal cramping
- Liver damage resulting in jaundice (yellow skin, tears, and urine)
- This grade of GVHD occurs in 1 out of 3 patients with a related donor and 3 out of 5 patients with an unrelated donor.

### **What is the treatment for more than mild GVHD?**

GVHD with more than mild symptoms is treated with high-dose prednisone. If GVHD does not improve, additional treatment may be needed. High-dose prednisone increases the risk for infections and other complications. Whether or not standard prednisone therapy controls the GVHD, the dose of prednisone is decreased over weeks or months, depending on your child’s response.

### **Failure to engraft**

Failure of the transplanted cells to grow and develop is an uncommon complication. At first, there may be signs of engraftment such as increasing blood counts, but later the blood counts decrease. Generally, it takes a number of weeks after the transplant to find out the success of the graft. It takes longer for some patients to engraft than others. The production of blood counts is not a steady climb. Blood counts normally fluctuate after transplant. Also, certain medications influence the production of blood cells.

If failure to engraft is indeed the diagnosis, then your child will be offered other therapies. Some treatment plans (research protocols) are focused on just this situation and aim to boost the production of blood cells. Other treatment plans involve stopping the drugs that interfere with bone marrow function or the infusion of reserve marrow or more stem cells if available.

## **Transitioning back to SCCA**

Allogeneic patients are admitted to Seattle Children’s during conditioning. The transition nurse will meet with you and your child to help with plans for discharge from the inpatient unit at Seattle Children’s. After discharge, SCCA nurses will coordinate your child’s care again.

Before leaving Seattle Children’s, you and your child will receive the information and have an opportunity to learn and practice the skills to manage care at home. Classes are taught demonstrating these skills, and all caregivers are welcome to attend any of the classes a second time to “brush up” on information or skills.

A transition nurse will schedule the first clinic visit before the day of discharge from the Inpatient Unit. Your child will be scheduled to see your care team at SCCA at least once a week, and other times as needed. This

clinic visit includes an exam and time for you to share your questions and concerns with staff. Also, on your child's first clinic visit, you will be given a weekly schedule for clinic times, blood draws, and routine chest X-rays. Your child will have a nutrition visit scheduled. Your child may also need to be at SCCA for care other than your scheduled weekly visit.

Blood will be drawn at the clinic in the morning, two to seven times a week. Bone marrow aspirations around day 28 and day 80 post-transplant are done by a nurse at the clinic to determine the status of the new marrow. Spinal taps (LPs) may be scheduled to administer therapy to the central nervous system. Intravenous medications, infusions, growth factors, study drugs, and blood product transfusions are also given in the clinic.

## Preventing infection

Even though your child is well enough to recover at home, his or her immune system is still recovering, and you will need to take precautions to guard against infection. We suggest that you do not socialize with other transplant patients, as a protection to your child. Use common sense to guide your decisions. For example, avoid crowds of people. This means that you may go to public places such as restaurants but avoid peak hours. And, of course, wash your hands.

## Temperature taking

Take your child's temperature twice daily, morning and night. Call the clinic or after-hours clinic for a temperature taken by mouth that is greater than or equal to 38.3°C or 100.9°F, or a temperature of 38.0°C 100.4°F for that lasts for 1 hour or more. When taking an axillary (under the arm) temperature with children, call if the temperature is 37.9°C or 100.3°F. **Do not take Tylenol® until you have talked with your child's care team. Report a shaking chill without a fever.**

## Plants and pets

Avoid plants. Do not keep fresh flowers and plants in your home. The organisms that may grow in water, dirt, and on plants can cause infections. Your child should not clean up after animals. Have your child wash his hands if a pet licks them.

## Other health maintenance activities

### Daily exercise

Regular exercise is important to your child's recovery. Physical therapy may be ordered. If your child is taking prednisone (steroids), your child may need physical therapy to maintain muscle strength.

### Sun safety

Use sunscreen with sun protection factor (SPF) 30 when outside and apply it to all exposed skin areas. Even if it is not especially sunny out, it is important to protect your child's skin from the sun's rays. Your child's skin is sensitive to the sun for 2 to 3 months after transplant. There is an increased risk of skin cancer after a transplant, so your child must continue to use sunscreen for the rest of his or her life. A GVHD rash appears from sunburn, even from slight overexposure.

### Symptom management

Review the Managing Care at Home section for more information on symptom management. The Quick Reference Guide in the pocket of this manual should be used for reference. If in doubt, give us a call. Keep your child's emergency card with you.

## **Readmission**

Your child may need to be readmitted to the hospital for management of symptoms that cannot be safely taken care of in the home setting or the clinic. As soon as your child is medically stable, the medical team will work with a transition nurse to have your care returned to the clinic.

## **Departure**

### **Departure evaluation**

Before leaving SCCA to go home, your child will have a series of tests done to detect any chronic graft-versus-host-disease (GVHD). Chronic GVHD usually starts around day 80 after transplant and can be present without causing any obvious problems to you. These screening tests can find early signs of GVHD, so if needed, you can receive treatment before further problems develop. These tests are scheduled around day 80 and take about one week to complete, and about 10 working days for the results to be available:

- Pulmonary function tests
- Skin biopsy
- Final bone marrow aspiration
- Blood tests
- Oral examination

The results of these tests are evaluated by a doctor who performs a physical exam and will make recommendations for chronic GVHD as you and your child make the transition to your home.

### **Departure conference and clinic visit**

About two weeks after your child's chronic GVHD workup is done, your family will have a summary conference with the attending physician and nurse. At this conference, you and your child will receive the results of the day 80 work-up and will be given recommendations and/or instructions for continued self-care and monitoring at home. You and your child will also have the opportunity to ask any remaining questions about your condition or your return home. Protocols may be offered for long-term care at home at this conference. Following this conference, you will have one final clinic visit with your care team.

### **Long-term follow-up departure class**

After you have left the clinic and you are home, the long-term follow-up staff will be a resource for you, your child, and your child's doctor. They are available during business hours to answer questions and concerns. You will be scheduled to attend the long-term follow-up (LTFU) class to learn how to take care of your child during the coming year.

### **Discharge papers**

Discharge papers consist of a packet of information that we ask you to take with you to give to your child's local physician. They contain a summary of all your care and recommendations for your further care. These papers will be given to you and your child during your final clinic visit.

## **Your child's transplant team and resources**

There are many people helping in your child's care while he or she is having a transplant. Together they are your care team. You and your child are the most important members of the care team. Talk with the other members of your team, and feel free to ask questions and share information. Your core team consists of an

attending doctor, primary doctor or physician's assistant, nurse, transition services (discharge planning), support staff, and consultants. Additional team members are described below.

### **Child Life Program**

Child Life promotes child development and helps your child maintain normal living patterns. This service helps your child cope with the stresses of illness. The Child Life Specialist uses medical play to explain treatment and procedures in language appropriate for their age and development. Child Life is available to help develop coping skills to care for a sick child.

### **Clinical pharmacist**

The clinical pharmacist makes recommendations on drug therapy and provides information about medications.

### **Guest Services**

To learn about Seattle and services for patients and families, please speak with our friendly Guest Services volunteers in the clinic's main lobby. Volunteers suggest recreational activities, acquaint you with SCCA and surrounding areas, distribute donated tickets for Seattle attractions and special events, provide wheelchair escorts, give directions, and call taxis and shuttles. They are available from 8 am–4 pm Monday through Friday.

### **Interpreter Services**

Interpreters are available for non-English, limited English-speaking, and hard of hearing or deaf patients and donors during medical consults, consent and department conferences, and during donor screening.

Interpreters are present during meetings with your team when you are learning how to manage your care and for getting updates on the progress of your treatment.

### **Living Tobacco-Free Services**

Living Tobacco Free Services are available at no charge. If you, caregivers, or family members are thinking about stopping tobacco use, you can call and speak with someone directly to discuss quitting, develop a quit plan, and get support during the quitting process. Free nicotine patches, gum, and lozenges are available to those who receive counseling.

### **Medical Nutrition Therapy Services**

The science of nutrition during cancer treatment is a specialized field. A dietitian will help you and your child understand the benefits of good nutrition to stay stronger and feel better during and after cancer treatment. Dietitians will work with your child to minimize side effects from treatment while helping choose foods your child enjoys eating. They also provide education on food safety while your child's immune system is compromised. A dietitian can provide recommendations based on food preferences and tolerances, interest in food, and specific social, economic, and medical situations. A visit with a dietitian can provide you and your child with inspiration about how to make healthful eating work even while your child is undergoing treatment.

### **Medical care for family members**

The clinic provides medical services to patients only. All other family members who need medical treatment while in Seattle have the following options:

- Go to their local doctor.

- Call Urgent Care at the University of Washington (206) 598-4000. Ask for an appointment with Urgent Care.
- Go to the University of Washington Medical Center, Family Medical Center Roosevelt Clinic (206) 548-4055, or Belltown Clinic (206) 443-0400. Any family member with symptoms of cold or flu should not come to the clinic or the Inpatient Units until checked by a nurse or doctor. Please contact your child's care team if you have questions or need help.

## **Oral medicine (dental health)**

The oral medicine service assists with the management of mucositis (sore mouth).

## **Patient and Family Education**

Knowledge is power! You and your child have the right to disease-specific information regarding treatment options, side effects, and maintaining your health after treatment. Ask your nurse for materials such as chemotherapy cards or symptom sheets. You can also visit [www.seattlecca.org/patient-education](http://www.seattlecca.org/patient-education) to access videos and documents about cancer care and treatment, and other helpful information.

## **Patient and Family Resource Center**

The Patient and Family Resource Center is located on the 3<sup>rd</sup> floor of the clinic. The Resource Center provides educational materials, computer workstations, a business center, notary, and a cancer literature lending library. It also offers wig fittings. Resource Center staff can provide listings for local and clinic events, as well as assistance locating support groups and other resources. All services and materials are free.

## **Patient Financial Services**

Patient Financial Services staff works with you and your insurance company to obtain approval for procedures and maximize your reimbursement for your care. Many insurance companies have managed care or case managers for you and your care team to access during and after treatment. They will need to be notified of new admissions, medical updates, and treatments during your care. Your insurance plan will determine what you are eligible for, including during care at SCCA (outpatient) and Seattle Children's (inpatient). They will also authorize payment.

## **Physical therapy**

Physical therapy plays a significant role in enhancing your child's quality of life as he regains his health. Physical therapy is highly individualized, and your child's specific exercises are based on his diagnosis, treatment, and expert knowledge. To schedule a physical therapy appointment, ask your care team for a referral.

## **Psychiatry and Psychology Services**

Psychiatry and Psychology Services are available for your child if they are experiencing difficulties coping. Specialized medication, coping skills, imagery, and behavioral techniques are some of the many options available for managing stress, depression, anxiety, pain, nausea, eating or sleeping difficulty, or other issues that are common during illness and treatment.

## **The Gift Shop**

The in-clinic store, The Gift Shop, is located on the 1<sup>st</sup> floor of the clinic. Product offerings include quality goods and items, convenience sundries, books and newsstand, gift items, hats, scarves, apparel, jewelry, cookbooks, stationery, snacks, and toys and games for all ages. Store hours are Monday through Friday,

8:30 am to 4 pm.

## **Shine**

Shine is located on the 1<sup>st</sup> floor at SCCA House, and provides specialty products such as skin care, hair alternatives, post-surgical apparel, compression garments, and light medical supplies. We carry physical therapy recommended products like light weights, exercise balls, heart monitors, and pedometers. Services include a private fitting room area, a head shaving station, and trained and supportive staff to assist customers in finding products. Appointments are recommended for fittings of custom compression garments. A shuttle departs from SCCA to SCCA House every 20 minutes. This is your most convenient way to visit Shine. Store hours are Monday through Friday, 10 am to 6 pm, and Saturday 10 am to 3 pm [www.seattlecca.org/shine](http://www.seattlecca.org/shine)  
Location: 207 Pontius Ave N., Suite 101, Seattle WA 98109

## **Social Work**

Social work services are available for you and your child. If you have an immediate need, you can ask your care team to page the social worker for a same day appointment if it is available. The social worker may be able to see you in the clinic that day or will arrange another time to talk to you. Otherwise, call your child's social worker number and please leave a message. Some of the services offered are:

- Information and referral to community resources.
- Help with insurance questions and public assistance programs.
- Counseling to help with coping with illness and life changes.
- Patient and family meetings for short and long-term care planning.
- Information on housing and transportation resources.
- Advocacy and help with problem solving at any time during your treatment.

## **Spiritual Health**

Chaplains provide respectful spiritual and emotional care for people of all faiths and spiritualities, including those who identify as non-religious or non-spiritual. Worship and other services are provided, as well as assistance in locating religious and spiritual resources. Visit the Sanctuary, located on the 1<sup>st</sup> floor, for quiet prayer, reflection, or meditation.

## **Supportive and Palliative Care Services**

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for you and your child, regardless of the stage of the disease. Palliative care can be delivered along with life-prolonging treatment. Goals include enhancing the quality of life, helping with decision-making, and providing opportunities for personal growth. Talk to your team and let them know you are interested in seeing the Supportive and Palliative Care Service provider. Appointments can usually be scheduled within one to two weeks.

## **Volunteer Services**

Volunteers provide practical and social support for patients, caregivers, and families in a variety of ways. Following are examples of ways that a volunteer can support you:

- Meet you and your child at the airport when you arrive in Seattle. Provide rides to and from the airport for primary caregivers.
- Help you get to know the city, provide transportation for grocery shopping, and run errands once or twice a week.

- Offer social activities and opportunities to take relaxing breaks, such as going out to lunch, visiting parks, and enjoying movies and sightseeing.
- Bilingual volunteers assist families who do not speak English, if available.
- Volunteers would like to help make your stay in Seattle as comfortable as possible. However, many volunteers work full-time and are unable to provide daily support.

## Information and services

Organizations that offer information and services to people with cancer and their families are listed below. Inclusion on this list does not imply endorsement by the SCCA.

|                                                                                                                                                      |                                       |
|------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|
| Seattle Cancer Care Alliance<br><a href="http://www.seattlecca.org">www.seattlecca.org</a>                                                           | (206) 606-1000                        |
| Fred Hutch<br><a href="http://www.fredhutch.org">www.fredhutch.org</a>                                                                               | (206) 667-5000                        |
| American Cancer Society<br><a href="http://www.cancer.org">www.cancer.org</a>                                                                        | 1(800) 227-2345                       |
| Cancer Hope Network<br><a href="http://www.cancerhopenetwork.org">www.cancerhopenetwork.org</a>                                                      | 1 (800) 552-4366                      |
| Cancer Lifeline<br><a href="http://www.cancerlifeline.org">www.cancerlifeline.org</a>                                                                | (206) 297-2500<br>or 1 (800) 225-5505 |
| Livestrong Fertility<br><a href="http://www.livestrong.org/we-can-help/livestrong-fertility">www.livestrong.org/we-can-help/livestrong-fertility</a> | 1 (855) 220-7777                      |
| Cancer Pathways (formerly Gilda's Club)<br><a href="http://www.cancerpathways.org">www.cancerpathways.org</a>                                        | (206) 709-1400                        |
| Save My Fertility<br><a href="http://www.savemyfertility.org">www.savemyfertility.org</a>                                                            | (312) 503-2504                        |
| National Cancer Institute<br><a href="http://www.cancer.gov">www.cancer.gov</a>                                                                      | 1 (800) 422-6237                      |

Publications available at the NCI website include:

Facing Forward- Life After Cancer Treatment  
[www.cancer.gov/cancertopics/coping/life-after-treatment](http://www.cancer.gov/cancertopics/coping/life-after-treatment)  
 When Someone You Love is Being Treated for Cancer  
[www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated](http://www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated)  
 Taking Time: Support for People with Cancer  
[www.cancer.gov/cancertopics/takingtime](http://www.cancer.gov/cancertopics/takingtime)  
 Eating Hints: Before, During and After Cancer  
[www.cancer.gov/cancertopics/coping/eatinghints](http://www.cancer.gov/cancertopics/coping/eatinghints)

Chemotherapy and You: Support for People with Cancer

[www.cancer.gov/cancertopics/coping/chemotherapy-and-you](http://www.cancer.gov/cancertopics/coping/chemotherapy-and-you)

Radiation Therapy and You: Support for People with Cancer

[www.cancer.gov/cancertopics/coping/radiation-therapy-and-you](http://www.cancer.gov/cancertopics/coping/radiation-therapy-and-you)

Caregiver Action Network

(202) 454-3970

[www.caregiveraction.org](http://www.caregiveraction.org)

Stupid Cancer

1 (877) 735-4673

[www.stupidcancer.org](http://www.stupidcancer.org)

### **Treatment/diagnostic information**

National Library of Medicine-Medline

1 (888)-346-3656

[www.nlm.nih.gov/medlineplus/druginformation.html](http://www.nlm.nih.gov/medlineplus/druginformation.html)

Radiology

[www.radiologyinfo.org](http://www.radiologyinfo.org)

Interventional Radiology

1 (800) 488-7284

[www.SIRweb.org](http://www.SIRweb.org)

### **Appearance**

Beauty and Cancer Program (UW Medicine)

(206) 598-3604

Look Good Feel Better

1 (800) 395-5665

[www.cancer.org/treatment/supportprogramsservices/look-good-feel-better](http://www.cancer.org/treatment/supportprogramsservices/look-good-feel-better)

### **Fitness/exercise**

Team Survivor Northwest

(206) 732-8350

[www.teamsurvivornw.org](http://www.teamsurvivornw.org)

### **Insurance**

America's Health Insurance Plans

1 (202) 778-3200

[www.ahip.org](http://www.ahip.org)

### **LGBT resources**

(212) 675-2633

National LGBT Cancer Network

[www.cancer-network.org](http://www.cancer-network.org)

### **Prescription drug assistance and issues**

1 (800) 503-6897

Needy Meds

[www.needymeds.org](http://www.needymeds.org)

### **Travelers with disabilities and medical conditions**

Transportation Security Administration

[www.tsa.gov/travel/special-procedures](http://www.tsa.gov/travel/special-procedures)

**Disease-specific websites**

National Bone Marrow Transplant Link  
[www.nbmtlink.org](http://www.nbmtlink.org) 1 (800) 546-5268

Leukemia & Lymphoma Society  
[www.lls.org](http://www.lls.org) 1 (800) 955-4572

Multiple Myeloma Research Foundation  
[www.themmr.org](http://www.themmr.org) 1(203) 229-0464

Aplastic Anemia and Myelodysplastic Syndromes  
[www.aamds.org](http://www.aamds.org) 1 (800) 747-2820

Myelodysplastic Syndromes Foundation  
[www.mds-foundation.org](http://www.mds-foundation.org) 1 (800) 637-0839

Sickle Cell Disease Association of America, Inc  
[www.sicklecelldisease.org](http://www.sicklecelldisease.org) 1 (800) 421-8453

**Sites for support and networking for youth**

Livestrong Young Adults  
[www.livestrong.org/we-can-help/young-adults](http://www.livestrong.org/we-can-help/young-adults) 1 (855) 220-7777

**Survivorship**

Livestrong Foundation  
[www.livestrong.org](http://www.livestrong.org) 1 (855) 220-7777

The National Coalition for Cancer Survivorship  
[www.canceradvocacy.org](http://www.canceradvocacy.org) 1 (877) 622-7937

The National Children's Cancer Society  
[www.thencs.org](http://www.thencs.org) (314) 241-1600

# Diagnostic imaging exams

## Type of imaging exam

- ☐ CT (computerized tomography)
- ☐ PET/CT
- ☐ DEXA (dual-energy X-ray absorptiometry)
- ☐ Mammogram
- ☐ MRI (magnetic resonance imaging)
- ☐ MUGA (multi-gated acquisition scan)
- ☐ Nuclear medicine bone scan
- ☐ Plain X-rays
- ☐ Ultrasound

## Prior to exam day

→ **Tell your physician and technologist if there is any chance that your child may be pregnant.**

- Prior to the day of your exam, please tell your care team if your child has an allergy to CT or MR contrast.
- See additional instructions specific to your appointment.
- Check with your child's care team to see what medications they should or should not take on the day of their imaging exam and any instructions to follow after the test regarding resuming medications.

## At the clinic before the exam

→ **Please arrive 15 minutes prior to your child's scheduled appointment time to allow for check-in and screening.**

- Medical Imaging/Radiology is on the second floor.
- Wear loose-fitting clothing without metal, such as zippers, belts, snaps or buttons.
- Remove all metal objects, such as hairpins, jewelry, eyeglasses, hearing aids, and any removable dental work that may obscure images.
- Your child may be given a gown to wear during the exam.
- Please turn your cell phones and/or pagers **off** before the exam begins.

## Preparing for a CT exam

### Food and fluid restrictions

- Do not allow your child to eat anything for 4 hours before their exam.
- She may continue to drink clear liquids\* until the scan.
- Check with your child's care team regarding what medications they should or should not take on the day of the imaging procedure.
- CT exams of the abdomen and/or pelvis may require your child to drink an oral contrast product during the hour before the scan time.
- If your child is given IV contrast, they will be required to remain in the imaging department for at least 30 minutes after the injection of IV contrast.
- If there are concerns about your child's kidney function, please check with your care team for special instructions for the exam.
- Your child may use the restroom any time before the exam unless instructed otherwise.

### \* Clear liquids are:

- Water
- Clear juices
- Tea
- Black coffee → **do not add milk, cream, or sugar**
- Clear broth

## Preparing for a DEXA exam (dual-energy X-ray absorptiometry)

- Eat normally, but don't take calcium supplements including TUMS® for at least 24 hours before the exam.
- Dress comfortably.
- Wear loose-fitting clothing without metal, such as zippers, belts or snaps & buttons.
- Your child may be given a gown to wear during the exam.
- Tell your child's physician and scheduler if they have recently had a barium exam or have received contrast material for a computed tomography (CT) or radioisotope scan; your child may have to wait 7 to 10 days before having a DEXA test.

→ Check with your child's care team for clarification of these instructions if needed.

→ **Tell the physician and X-ray technologist if there is a chance that your child may be pregnant.**



## Preparing for a mammogram

### Scheduling

- Schedule your mammogram for the **week after your period, or at least two weeks before** your next period. This is when your breast tissue is less sensitive. If you no longer have periods, any time of the month is fine.
- Before setting a date for a mammogram, talk to your physician about any **new findings or problems** in your breasts. Inform your physician of any past surgeries, hormone use, and family or personal history of breast cancer.
- Tell your physician and technologist if there is any chance you may be **pregnant**.
- **If you have had any prior mammograms**, please have them sent to Breast Imaging. Breast Imaging needs to review previous mammograms 48 hours prior to your exam in order to have them prepared for comparison. Send mammograms to:

Seattle Cancer Care Alliance  
825 Eastlake Ave East  
SCCA Radiology Film Room G2209  
Seattle, WA 98109

### Preparing for the appointment

- **Please arrive 15 minutes before** your scheduled appointment time to allow for check in and screening.
- Please wear a two-piece outfit, as you will be asked to remove all your clothing and jewelry above the waist. You will be given a gown that opens in the front to wear during your exam.

### Before your mammogram exam

- Wipe off any deodorant, talcum powder, or lotion under your arms or on your breasts. These can appear on the mammogram as spots. You will be given special wipes at your appointment to cleanse your underarms and breast.
- You will be asked to remove all jewelry and clothing above the waist, and you will be given a gown or loose-fitting material that opens in the front.
- Please turn your cell phones and/or pagers OFF when your exam begins.
- Report any unusual findings, such as a lump, thickening, redness, or swelling, to your physician and the technologist.
- Tell your physician and technologist if there is any chance you may be pregnant.

→ **Some women avoid having a mammogram because of anxiety or fear. Remember that having a mammogram is a way for you to stay healthy. The mammogram can catch problems early, which often leads to a complete cure.**

## MRI screening form

Your child's physician has ordered an MRI exam.

→ Call (206) 606-1434 if your child may be pregnant or weigh more than 300 pounds.

→ Review complete "MRI Patient Screening Form" for additional conditions that may affect the exam.

- In most cases, surgical staples, clips, pins, and screws are not a risk during MRI if they have been in place for more than 4 to 6 weeks. If there is any question of metal fragments in the eye, an X-ray may be done to check for them.
- To prevent a delay or cancellation of your child's exam, if they have **ANY** of the following implanted devices, allergies, or may be pregnant (see complete list below) please tell your child's team coordinator or call (206) 606-1434 to review their eligibility for the exam.
  - Pacemaker / defibrillator
  - Cerebral (brain) aneurysm clip\*
  - Cochlear implant\*
  - Cardiac stents\*
  - Implanted or external drug pump (including chemotherapy)
  - Breast tissue expander
  - If pregnant, # of weeks: \_\_\_\_\_
  - Dialysis or renal failure
  - Allergy to CT contrast or gadolinium
  - Drug or contrast allergies

Please bring the wallet card that identifies the implanted devices.



## Preparing for nuclear medicine bone scan or MUGA exam

- Increase your child's fluid intake before and after the injection. Encourage them to drink 3 to 4 glasses of their preferred drink after the injection. Encourage them to empty their bladder frequently.
- There are no eating or drinking restrictions.
- If your child is unable to remain still for 45 minutes, please speak with their referring physician for pre-medication.
- You will be given a document that states the period of time during which the small amounts of radiation remaining in your child's body are capable of detection by radiation monitoring equipment. This amount of radiation poses no danger to the public and is allowed by the State of Washington medical use regulations.

→ Young women who are pregnant or breast feeding should not have this exam.



## Preparing for an ultrasound exam

- If the abdomen will be studied, your child must not eat or drink anything for at least 8 hours before your exam.
- Medications may be taken with a small amount of water.
- For pelvic exams, your child must drink at least 16 ounces of water before the exam to fill their bladder. Do not go to the bathroom until instructed by the technologist.

→ If your child is diabetic, check with their physician or nurse about dietary and medication restrictions.



# **Participating in research**

## **Clinical missions**

By choosing to come to the SCCA, you, your child, and your family directly benefit the knowledge gained by previous patients who participated in various research studies. You and your child, in turn, may be asked to participate in similar research studies. The results may benefit your child as well as future patients. By working together, results can be improved. We believe that the goals of patient care, teaching, and research work together for the benefit of patients.

## **How research studies are developed**

Research studies are first developed by a staff member working in a specialized field of study. A proposal is written and shared among staff members working together, and then among the members of a scientific staff review committee. After review, the research proposal is turned into the Institutional Review Board. Their task is to ensure that being in the study is reasonable in terms of benefits and risks. They also review the written consent form to be sure that it clearly describes what will be done and the possible risks.

## **Informed consent**

You will be asked to sign a written consent form for each research study in which your child participates. Your signature indicates that the study has been explained to you, that you understand the risks, that you have had a chance to ask questions, and that you freely agree to participate. Consent forms also state that you remain free to withdraw your consent and your child from participating in the research study.

## **Benefits and risks of research**

It is often a possibility that your child will personally benefit by participating in research studies. There is also the possibility that your child will not benefit or that a harmful reaction may occur. Some studies involve assigning patients to a treatment by a process called “randomization.” This means that treatment will be decided by random computer selection. This is often done when it is not known whether one treatment is better than another. Comparisons are often made between a “new” treatment and a “standard” treatment. Randomization is a way to avoid any bias that might influence results of the comparison. It increases the confidence that any differences seen between groups reflect the effect of the treatment rather than other factors. You may feel uncomfortable about having aspects of your treatment decided by random computer selection. You might believe that the “new” treatment is likely to be better than the “standard” treatment, or you might be concerned that the “new” treatment may increase the chance of side effects. For either of these reasons, you may prefer to choose one treatment or the other. These feelings are understandable; however, we hope you will understand that there is no factual basis for any preference between treatments in this situation. If there were, we would not need to do a research study to find out which treatment is actually better.

## **Long-term participation in research**

Being involved in research will likely extend beyond your child’s stay at SCCA, especially if your child has problems that need ongoing treatment. We are able to carry on this research by working with her doctor. You and your child may be asked to return for a periodic check-up.

## **Research results**

Information gained from research studies is reported at scientific meetings and published in medical journals. In this way, we are able to share results with other professionals.

## **Confidentiality**

Patient confidentiality is always protected. Names and initials are not disclosed in any report. Records are kept locked and access is limited to authorized staff.

## **Questions about research**

Care is taken to ensure that your child's treatment is not endangered by participation in research. If you have concerns about being in any research study, we hope that you will feel free to ask questions. Your child's continued participation remains essential, and we are grateful for your willingness to work with us. If you would like to know more about clinical research, please ask your care team.

## **Financial interest in medical research**

Medical researchers occasionally have financial relationships with private industry, such as:

- Owning shares of stock
- Serving on advisory boards or consulting for companies
- Receiving consulting fees and payments

A medical researcher who has such an interest or relationship is required to disclose it. Institutions carefully review these disclosures. Decisions are made as to whether the study can be carried out by the medical researchers and whether the personal financial interests and relationships can continue. We do this to safeguard patients and the integrity of the medical research.

## **Connection with private industry**

For many years, medical researchers and private industry have worked together to study ideas that might become useful to science and patients. Drug companies and biotechnology firms sometimes pay for medical research studies. This financial support can lead to new ways to prevent, diagnose, and treat illness.

## **Our commitment to your child**

SCCA and its member institutions are committed to protecting the rights and well-being of participants who volunteer for medical research studies.

SCCA's member institutions have policies and procedures for the disclosure, review, and management of the financial interests and relationships between medical researchers and private industry.

## **If you wish to learn more about policies and procedures**

Each member institution has its own methods for review of financial relationships and interests. If you wish to learn more about these policies and procedures, you may contact the resources listed here.

### **Fred Hutch and Seattle Cancer Care Alliance:**

- SCCA Patient Relations: (206) 606-1056
- Institutional Review Board: (206) 667-6567
- The principal investigator of your study

### **UW Medicine:**

- The principal investigator of your study
- Human Subjects Division: (206) 543-0098
- Office of Regulatory Guidance (Office of Research and Graduate Education): (206) 616-8222

**Seattle Children's:**

- The principal investigator of your study
- Institutional Review Board: (206) 987-2023
- Seattle Children's General Counsel: (206) 987-2044

## Chapter 2 – Finding Your Way



## **Treatment at SCCA**

Care and treatment is provided at SCCA when possible. This allows you and your child to stay in the comfort of your home or temporary residence.

### **Your local phone number**

Please give us your local phone number so we can reach you when needed. Please include the patient's name in your message so our staff can be sure they reached the correct number. The receptionist keeps a current list of local phone numbers to reach patients and family members. Please keep the receptionist informed of your current local phone number and address. For your convenience, a pager will be available for your use.

### **The mail system**

Your child's mail is sorted by the receptionist and kept behind the reception desk on the 6<sup>th</sup> floor. Please ask the receptionist to check your mailbox for appointments and messages every day your child receives care in the clinic.

### **Appointments**

Your child's schedule and your child's donor's schedule will be coordinated by your team coordinator. Your team coordinator will meet with you to go over the details of the schedule. He or she will keep you informed of all changes and additions to your schedule. Please check in with the receptionist in the waiting area for all clinic appointments. You or a family member must check your mailbox every time you are in the clinic so you do not miss any appointments.

### **Chest X-rays**

Your child may be scheduled for a routine chest X-ray at Seattle Children's on the 4<sup>th</sup> floor, main Radiology department. Chest X-rays will be scheduled for your child as needed.

### **Radiology**

If you are scheduled for certain procedures such as a magnetic resonance imaging, computed tomography, or an ultrasound, you will need to go to Seattle Children's on the 4<sup>th</sup> floor, main Radiology department.

### **The Apheresis Unit**

The Apheresis Unit is at SCCA on the 5<sup>th</sup> floor where procedures such as stem cell collection and red blood cell depletion are done.

### **Pharmacy**

The transition services staff will confirm sources of oral and IV medications. The Pharmacy is located on the 5<sup>th</sup> floor of SCCA and is open from 8 am to 8 pm, Monday through Friday, and 8:30 am to 5 pm on Saturday and Sunday. New medication orders can be picked up anytime the pharmacy is open. All refills must be called in 48 hours before the day that you need your refill medications.

### **Resources and announcements for families**

Notice of clinic activities will be put in your mailbox and posted in key spots throughout the clinic. Family member activity schedules will be communicated via the mailbox system. Other activity information and tickets for special events can be obtained from the Guest Services information desk located on the 1<sup>st</sup> Floor of SCCA.

## **Release of medical information**

Clinic medical information can be obtained from SCCA Health Information Management. You will be asked to sign an authorization form to release health management information. There is no charge for records released to you or your physician.

## **Sick family members**

Family members showing symptoms of cold or flu should not come to SCCA until they have been checked by a nurse or doctor. Contact your care team for more information.

## **Fresh flowers and plants**

Fresh or dried flowers and plants are not allowed at SCCA because of the organisms that grow on them and in their dirt or water, which can cause infections. Latex-free balloons and silk flowers are okay. Make sure there is not decorative moss around silk flowers. Only artificial moss is allowed.

## **Smoke free environment**

Smoking is not acceptable at SCCA. It is necessary to leave the Fred Hutch and SCCA campus premises in order to smoke. Washington law prohibits smoking within 25 feet of all entrances, exits, windows, and ventilation system of public places. Contact the Living Tobacco Free Services to sign up for smoking cessation or call the Washington State Quit Line at 1 (800) 784-8669 (1 (800) QUIT NOW) for free treatment or referral to other resources.

## **Guest wireless internet access guide**

Seattle Cancer Care Alliance is proud to offer free wireless high-speed Internet (Wi-Fi) access to our patients and visitors. Guest Wireless works with most wireless-equipped computing devices. For your convenience, connectivity is available throughout SCCA, including in patient rooms and visitor waiting areas. To connect to the Wi-Fi network, follow these steps:

- Enable the wireless feature on your device.
- Connect to the “SCCA-Guest” network.
- Once you are connected, open your web browser. Upon your first attempt to navigate to a website, you will be redirected to the Acceptable Use Policy Logon Page. You must read and accept the policy, by clicking “I Accept” at the bottom of the page. After accepting the policy, your browser will automatically load the Seattle Cancer Care Alliance homepage.
- You can now browse the web normally.

## **SCCA secure email**

To ensure the confidentiality of personal health information that SCCA sends you via email and to comply with Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations, an email encryption service is used. Encrypted emails, also called secure email or secure messages, help keep your personal health information private. This secure email site requires some extra steps, but we are confident it will allow us to communicate with you safely and efficiently by email. Each email sent will include brief instructions on how to access the secure email site. For more information, please visit the secure email page on our website at [www.seattlecca.org/scca-secure-email.cfm](http://www.seattlecca.org/scca-secure-email.cfm).

## **Inpatient treatment**

### **Location**

Seattle Children's provides inpatient and some procedure services for Seattle Cancer Care Alliance pediatric patients. The hospital is located at 4800 Sand Point Way N.E., Seattle, WA 98105. This is in northeast Seattle near the University of Washington. Seattle Children's provides care for bone marrow transplant and other cancer patients on Forest 7 (200/300 wing) and Forest 8 (300 wing), the SCCA patient-care unit.

### **Admission to the inpatient unit**

When you arrive at the SCCA, our staff will automatically pre-register your child at Seattle Children's so admission will be smooth. If your child's admission to Seattle Children's inpatient unit is scheduled in advance, you will be given the time and date to go to the hospital by the clinic staff.

Outpatients may develop symptoms that require hospitalization. Your SCCA care team can coordinate these admissions at any time. Remember to bring wall decorations from home and toys/games. Patients of all ages can bring their cell phones, tablets, and laptops to keep in touch with family and friends at home. Seattle Children's offers interpreter services for deaf, hard of hearing, or non-English speaking families. To request these services, ask your child's care team, or you can find their contact number in the important numbers section of this manual.

If the hospitalized infant is less than 120 days old, bed sharing is not recommended. It is recommended for the infant to be placed on a "bassinet" style sleep surface, if available, next to the parent's couch. If airway support equipment cannot be safely used in the bassinet sleeper, this option should not be used. A crib should remain in the room for infant assessment.

### **Contacting the unit**

Please see lists of numbers for contacting the unit in the important numbers section of this manual.

### **The Family Resource Center at Seattle Children's**

The Family Resource Center on the 5<sup>th</sup> floor, near the Train elevators, offers information about hospital services, community resources, books and pamphlets on child health issues, magazines, and free coffee, tea and cocoa. It is open 7 am to 10 pm daily. It is staffed 9 am to 9 pm Monday through Friday, and 1 to 9 pm Saturday and Sunday. The hospital chapel is located inside the Family Resource Center. For more information please call the number listed in the important numbers section of this manual. Caregivers need to take breaks and care for themselves in order to continue to care for their child.

## **Your child's daily routine**

You may wonder what the normal routine day is like for your child in the inpatient unit at Seattle Children's. Remember, there is still time to play, when your child is feeling up to it. What procedures are often done? What tests are usually run? What routine activities will be a part of everyday life on the unit? Routines will be explained in more detail by the inpatient nurse, but in the meantime, here is an overview of what you can expect.

## **Rounds**

Every morning the physician and other members of your child's care team will round with each child and family. This is to check on your child's progress and to make changes in therapy if needed. This is a good time to ask any questions you or your child may have and to discuss the plan of care. You can ask the day nurse what time rounds are in the morning.

## **Physical examinations**

The nurse and doctor will, at different times, need to listen to your child's heart and lungs with the stethoscope. They press lightly and listen to his abdomen with a stethoscope to check for sounds indicating normal functioning of the stomach and intestines. The nurse will look at your child's mouth daily and more frequently during the period he is likely to experience mucositis, an inflammation of the mouth.

## **Routine blood tests**

Early morning, from 4 to 6 am, the nurses will draw daily routine blood tests from your child's central line. We will disturb you and your child as little as possible, but our medical team needs to review the laboratory findings as early in the day as possible.

## **Vital signs**

Your child's temperature, pulse, respiration, and blood pressure, all of which we call "vital signs", will be taken every four hours as a standard so as not to allow too much time to lapse before we see any change in your child's condition. Sometimes they are taken more often if we need to monitor her more closely.

## **Daily weight**

A daily morning weight check is important to monitor the amount of fluid in your child's body. Occasionally, she may need to have her weight checked twice per day.

## **Chest X-rays**

Chest X-rays to check your child's lungs are done weekly, or more frequently, depending on your child's health.

## **Medications and IV fluids**

Many medications such as antibiotics, anti-nausea medications, or medications to prevent graft-versus-host-disease will be given through the central line. Other fluids will also be given when your child cannot drink to help keep up fluid intake. Parents may give oral medicine to their child only after being instructed by a nurse.

## **Getting help from a nurse**

Please use the nurse call button for help if an alarm rings in the patient's room. Your child will have medications and fluid running on infusion pumps. These pumps have alarms that will beep for various reasons. Family members should **not** correct the pump alarms.

## **Transfusions**

Blood and platelet transfusions will be given to your child as needed until she is able to make her own blood cells. Blood counts will be checked every morning.

## **Nutrition**

Dietitians will talk to you and your child about his food likes and dislikes. Patients who are not able to eat are given total parenteral nutrition (TPN), also known as hyperalimentation (HA). This goes through the central line and has no taste.

## **Recording intake and output**

If you give your child food, water, or ice, notify the nurse of the amount given. It is important to keep accurate records of fluid intake and output. Therefore, never empty a urinal, bedpan, or emesis (vomit) basin. Your child's nurse will do that for you.

## **Exercise**

Your child may feel like she is always connected to some medication going into the central line. We encourage you to arrange with the nurse a time to take a walk and exercise in the halls. The doctor may order a physical therapist to visit your child to help keep her activity level up.

## **Bathing, showers, and oral care**

Daily baths are taken to help cleanse the body of bacteria. This may help lower the chance of infection. Mouth care is also an important part of the transplant. We will encourage your child to do rinses with mild salt water called "normal saline" to help remove bacteria and promote healing. There's a shower in each room that patients and families can use. Coordinate with your nurse to sign up for a bathroom time to use a bath tub.

## **Central line care**

The central line dressing will be changed as necessary to guard against bacterial growth. This gives the nurse a chance to inspect the skin around the central line. Nurses will check under the dressing at other times as well.

## **Making the transition to recovery at home**

A transition nurse will meet with you and your child to help with plans for discharge from the inpatient unit at Seattle Children's. Care will then be coordinated by the care team at SCCA until your child is discharged from care to return home. This is the same care team that prepared your child for transplant and monitored the progress of his therapy until he was admitted to the inpatient unit.

## **Visitor guidelines**

### **Open visiting hours**

Parents may be with their child 24 hours a day. Visiting hours for siblings and others are 10 am to 8 pm. We encourage families to keep their own health in mind and to get a good night's sleep. One parent/legal guardian may stay at the bedside overnight. Siblings and other visitors may not stay overnight in the hospital. A nurse will contact family members at home if any problem occurs.

### **Siblings**

Children are important members of a family, and we encourage them to visit during their hospital stay. These guidelines are for brothers, sisters, and other child or teen visitors:

- Wash their hands like any other visitor.
- Those who are ill or might be ill are not allowed to visit.
- Those who have been exposed to chickenpox and who have not had chicken pox before are not allowed to visit.

- Those who have received live-virus oral polio vaccination cannot have contact with the patient for at least 6 weeks. If a child needs polio vaccination, the inactivated polio vaccine can be given by injection.
- May not go into the room of another patient.
- Children under 10 years old must be with an adult when playing in the family room or teen room. Toys from the family room may not be taken into the patient's room.
- The hallway is not a play area for children. Children are not allowed to play with hospital equipment such as wheelchairs and stretchers.

## **Receiving mail at Seattle Children's**

Friends and relatives may send mail to your child by addressing it to the following:

Your Child's Name  
Hematology/Oncology Unit  
P.O. Box 5371, MS CH-58  
Seattle, WA 98105-0371

## **Local phone number**

Family members should make sure that the unit coordinator has their correct phone number on file for emergency use.

## **Preventing infection**

Patients and family members are not allowed to visit other patient rooms. This helps to prevent the spread of infection. Patients are encouraged to walk around the patient care unit, but should avoid other patients, their families and the areas where people gather. Family members or other visitors should not use the bathrooms in the patient's rooms. There is a danger of infections both to the patient and to the visitor. Public restrooms are located on all nursing units.

- Keep surfaces clear of patient/family belongings. Some organisms can survive a long time on the surfaces and equipment in the patient's room. It is very important that these surfaces be cleaned daily by Environmental Services (ES). The ES staff cleans bed rails and other items close to the patient if the patient is present. To help them do a complete cleaning, please leave the room if possible. Taking a shower, a walk, or sitting in a chair are options.
- Minimize the number of personal belongings in the room. We encourage patients to have cards and pictures posted on the wall of their room. Other items should be placed in the patient's bedside cabinet. Family members can help by taking items sent to the patient by other family members and friends back to the home or apartment shortly after the patient sees them.
- Clean or wash the patient's personal belongings. Environmental Services staff does not clean patient's personal belongings. Daily, a family member or friend should wipe off the patient's personal belongings, toys, and play activities provided by the hospital, with a cloth or paper towel dampened with soap and water. Hospital toys can also be put in the waiting room to be cleaned by volunteers. Items such as clothing or quilts should be washed periodically or when they become soiled.

Here are a few reminders of procedures that also prevent the spread of infection:

- Place used tissue in the trash can, not on other surfaces such as the bedside table or floor.
- If you have a son who is using a urinal, please place it on the floor, not on the bed rail or on the bedside table or bedside cabinet. Please ask for help if you are not able to put it on the floor safely.

- You and your child need to wash hands frequently, before eating and after using the bathroom or urinal.

## Summary of infection control concerns

It can take as much as a year for the infection-fighting immune system to get back to normal. It is important to make the steps in preventing infection a part of daily life. Germs and bacteria, which can cause infection, are present everywhere in the environment, as well as on and in a person's body. Even when careful attention is paid to infection prevention procedures, it may not be possible to prevent infection during the entire recovery period. Be sure to seek medical care at the first sign of infection so treatment can be started early.

Any family member or visitor who has a fever or cold, or who is not feeling well, should not come to visit the patient. Even minor colds and infections carry a risk to the patient. Children, in particular, are known to get many viruses. Please evaluate the health of children, and their exposure to other children that may have been ill, before letting them come to the inpatient unit. If a family member needs to see a doctor, ask your nurse for a referral.

Handwashing is the single most effective way to prevent the spread of infection. Before entering and when leaving a patient's room, everyone is expected to follow a simple but thorough handwashing procedure.

## What to bring from home

Bring wall decorations and your child's favorite toys and games. Patients of all ages can bring their cell phones, tablets, and laptops to keep in touch with family and friends at home.

## Service dogs, therapy dogs, and pets

Healthcare facilities and other places that serve the public must allow people with disabilities to be accompanied by their service dogs. **At SCCA, service dogs can accompany handlers in all areas of the clinic, except for in rooms where invasive procedures and imaging take place.**

A service dog is a dog that is individually trained for the purpose of assisting or accompanying a disabled person's sensory, mental, or physical disability. The special training service dogs receive is more than obedience training or positive reinforcements that are given to family pets. Service dog handlers are protected under the ADA because of the disability the handler experiences.

A therapy dog is trained to provide affection and comfort to people. A therapy dog's primary job is to allow people (who may or may not have disabilities) to make physical contact with it and enjoy that contact. Although the emotional benefits of therapy dogs are significant, physical contact to the dog is an infection concern in cancer centers that serve patients with weakened immune systems. **This is one of the reasons why SCCA does not allow therapy dogs, other therapy animals, or pets. Please do not bring therapy dogs, therapy animals, or pets to the clinic.**

## Fresh flowers and plants

Fresh flowers and plants are not allowed in your child's room. There are organisms that grow on them and in their dirt or water, which can cause infections. Mylar balloons and silk flowers are okay. Latex balloons are not allowed at Children's Hospital.

## Money and valuables

Money and valuables should not be left in your child's room or the family room because of the risk of theft. There is a safe box in each room that you can access with your chosen code.

## Family Space/kitchen

All who use these areas must help to keep them clean. There are two family spaces, one quiet space and one play area for siblings by the unit coordination desk. Transplant patients cannot use these areas because of infection concerns. If you bring food into the Family Space, please clean up food items before leaving the area. You are encouraged to use this as a quiet space for reading, conversation, and other relaxing activities. Each patient room has a small refrigerator. Items that need to be in the freezer can be placed in the family room's freezer labeled with your child's name.

## Teen Space-3B

Teen Space is a hang-out for siblings 12 to 21 years of age. Adults must be accompanied by their teenager. If you have any questions or requests, you can call Child Life at x3646. Please help us keep the Teen Space safe and clean by following these infection control guidelines:

- **Wash your hands** as you enter the room. The nearest sink is in the Family/Play Space.
- **If you are ill, please do not enter the Teen Space.**
- **Please place any games, craft materials, and other items that get soiled into the "Clean Me" bin!** If it's sneezed on, coughed on, or has come into contact with any bodily substances, it qualifies for the "Clean Me" bin.
- **Please do not bring food into the Teen Space.** You can eat in the Family/Play space.



## Chapter 3 – Managing Care at Home



“There are only four kinds of people in this world:

Those who have been caregivers

Those who are currently caregivers

Those who will be caregivers

Those who will need caregivers”

-Quote from Rosalynn Carter’s colleague

Rosalynn Carter’s book Helping Yourself Help Others begins with the above quote. Education and support have been developed to meet the needs of your child and family caregivers. Weekly group classes, videos, individualized instruction, and written materials are offered. Support is offered by team members including nursing, social work, and spiritual health. Please review the next two sections for details of caregiving.



## **Suggestions for coping with care at home**

- Ask questions. If you are not sure, call using the important phone numbers provided.
- Remember that you and your child are members of the team, and your input is important. Keep your nurse and doctor informed.
- Review the symptom sheets provided and call for help if needed.
- Review hints for self-care.
- Ask your family and friends for help before you are too fatigued. Keep a list of what friends can do, and delegate. For example, one person could make a meal and another could go to the grocery store. Some people have more time than others; this is where your list would be helpful.
- Organize the day into manageable segments. Develop a schedule each day and week. This process allows family members or friends to be in agreement with the goals for the day or week. If everyone is working with the same agenda in mind, the tension within a family usually decreases.
- Remember, the staff at SCCA is here to support you as well. Tell your care team, including your social workers, if you need more support.
- Use websites to keep family and friends informed: [www.caringbridge.com](http://www.caringbridge.com) or [www.carepages.com](http://www.carepages.com)

## **Outline of typical caregiver responsibilities**

### **Making arrangements:**

- Transportation.
- Financial.
- Tracking appointments.

### **Giving emotional support:**

- Being physically present.
- Giving encouragement.

### **Providing physical care:**

- Identifying changes in patient's condition.
- Reporting patient's symptoms to healthcare staff.
- Obtaining medical care if needed.
- Monitoring patient compliance in self-administration of oral medications.
- Recording medications taken/administered.
- Acquiring and maintaining medical supplies.
- Performing tasks such as central line care.
- Administering fluids and medications using an intravenous pump.

### **Maintaining the home environment:**

- Cleaning.
- Food preparation.
- Shopping.

### **Patient advocacy:**

- Gathering information and assuring that pertinent information is given to medical staff.
- Helping with decision-making.

### **Providing assistance and support to others:**

- Serving as a communication link with other family members or friends.
- Imparting information to children.
- Providing child care.

## **Taking care of the caregiver**

Caregivers are encouraged to take care of themselves through exercise, proper diet, and adequate sleep. Caregivers benefit from breaks. Caregivers are at risk for becoming ill if they ignore their own health.

Here are some helpful tips from Rosalynn Carter's book about caregiving, Helping Yourself Help Others:

- Listen to your friends. Be open to others' observations.
- Let go. Know your limits.
- Focus on your loved ones' strengths.
- Learn relaxation techniques.
- Take care of your health.
- Maintain a life outside your caregiving role.
- Insist on private time.
- Build a caregiving team.
- Rely on your sense of humor.
- Appreciate the benefits of leisure time.
- Help your loved one find a support group.
- Seek professional help.
- Appreciate your own efforts.
- Seek spiritual renewal.

### **Develop a plan of care**

The nursing staff will work with you to develop a unique home care plan. You and your child have a nurse available 24 hours a day to answer questions. Other family members and friends can help during different stages of transplant with various tasks. Caregivers need to develop a schedule and division of tasks that is satisfactory to all. Your child can participate in self-care, as long as they feel well enough to do so. Other adult family members can learn to operate the ambulatory pump. When a different person takes over line care, they should review the steps with a nurse.

The home care plan should meet safety needs. The following recommendations give an idea of the different levels of caregiving needed throughout the transplant and recovery process. Each patient and family organizes their routines differently. Some patients and families like to keep a logbook of activities, infusions, and medications. Please see the examples of a home care schedule at the end of the manual.

### **Recommendations for caregiver support**

We hope these recommendations will assist families in anticipating the need for caregiver support. Needs change throughout the transplant process.

**Clinic phases and support levels:** Young children need consistent support on an ongoing basis. Older children in late teens and young adults may reach a point when intermittent or minimal supports are appropriate.

- **Consistent support:** Caregiver is present most of the time; breaks should be less than three to four hours. Adult patients, but not children, can be left alone if they have access to the phone, the ability to contact emergency services, operate ambulatory pumps, get to the restroom, and have access to food and fluids. Criteria for recommending a consistent caregiver for the patient are:
  - During conditioning (including Dilantin® administration), chemotherapy, and radiation therapy
  - First 1 to 2 weeks in at SCCA after initial discharge from the hospital after transplant
  - Three different IV infusions such as hydration, medications, or hyperalimentation over a 24-hour period
  - Neutropenia (ANC < 500)
  - Altered mental status: drowsy, confused, impaired judgment, poor memory
  - Weakness/limited mobility (cannot walk without assistance)
  - Sliding scale insulin (when starting therapy)
- **Intermittent support:** Does not need a caregiver for the majority of hours within a 24-hour period. A caregiver is available 2 to 3 times per day to provide assistance with dressing changes, medications, transportation, and processing information provided during conferences or clinic visits.
- **Minimal support:** Patients do not require a caregiver but do benefit from emotional support during clinic visits and conferences.

## Patient and caregiver education

Patient and Caregiver Education is an integral part of treatment and services offered. Informational, educational, and support services are available to patients, family members, and caregivers. You have the right to information regarding health status, disease, treatment options, the treatment process, managing and monitoring health in the home setting, and maintaining health after treatment. Patient and caregiver education has three major components:

- Individual teaching
- Classes
- Videos

Individual teaching is offered on topics such as care of the central line, medications, blood glucose monitoring, and specific needs that may arise during the treatment and recovery process. Educational classes focus on gaining an understanding about the treatment process and developing the skills needed for the patient's treatment, and recovery in the home setting.

You can visit [www.seattlecca.org/patient-education](http://www.seattlecca.org/patient-education) to access videos and documents about cancer care, treatment, and other helpful information.

## **Class descriptions**

Classes are scheduled by the clinical support staff. A personalized list of appointments and scheduled classes is placed in your patient mailbox.

### **Managing care at home and review of transplant process**

This class includes an overview of the bone marrow/stem cell transplant process, review of the patient/caregiver role and resources and how to prevent infection. Content of this class includes managing symptoms, emergency plan development (mucositis, dehydration, diarrhea, bleeding, and breathing problems), and adjusting to recovery at home.

### **Food safety**

The content of this lecture and discussion class includes the rationale for food safety, foods to omit, safe food selection, and proper food handling techniques including cooking, preparation, and storage.

### **Long-term recovery class**

Information on how to manage care after leaving the Center is presented. Content includes immune system recovery, assessing symptoms, treatment of graft-versus-host disease, guidelines for daily living, and coping with the common psychological reactions after transplant.

## **Guidelines for preventing infection**

### **What is an infection?**

Infections are caused by germs, which are also called microorganisms or microbes. Germs cause illness by entering the body and multiplying. Typical germs that can infect transplant patients are bacteria, viruses, and fungi (molds and yeast).

During transplant, your child's immune system will be weak, so he or she will be at a higher risk for getting infections. Infections after transplant are more serious than in those people who are otherwise healthy. It is critical to limit exposures to sources that might increase your child's risk for acquiring an infection, and to seek help when your child develops infectious symptoms. While it is not possible to prevent all infections, there are a number of simple steps that you and your child can take to help prevent many common infections. While this section cannot cover all scenarios or possible situations, it includes basic information on how to prevent infections during your child's transplant.

### **Clean your hands often**

Cleaning your hands is one of the best ways to prevent infections. Hand hygiene is key, especially during the first year after your child's transplant and/or while he or she is taking immunosuppressive medicines (medicine that weakens the immune system).

You, your child, and anyone you come into contact with, including all members of your household, your doctors, and nurses, should clean their hands frequently. Do not be afraid to ask visitors or healthcare staff if they cleaned their hands before they meet with you.

There are two options for cleaning hands. Standard washing with soap and water is a great way to clean your hands. Alcohol hand sanitizer (hand gel such as Purell®) is another good way to reduce the number of germs on your hands. For home use, be sure to select a hand sanitizer that contains at least 60% alcohol. Hand

sanitizers are not as effective when hands are visibly dirty or greasy. Also, keep in mind that these hand sanitizers do not prevent some gastrointestinal infections, such as *C. diff* and norovirus. Persons with these infections and their caregivers should wash their hands with soap and water instead. At SCCA, Seattle Children's, and UW Medical Center, hand sanitizer is located in elevator lobbies, waiting rooms, and exam rooms. Please use hand gel frequently.

Keep nails short. Germs like to hide under fingernails. Avoid the use of artificial nails.

### **When should you clean hands?**

It is important for all family members to clean hands frequently throughout the day, particularly when you are in public places (SCCA, Seattle Children's, restaurants, shopping, common areas, and waiting rooms). Some specific times that are important to make sure you clean your hands:

- Before eating.
- Before and after preparing food.
- After touching pets or animals.
- After sneezing, coughing, or blowing your nose.
- After going outdoors.
- Before and after any central venous catheter care or intravenous infusions.
- Before taking oral medicines.
- Before entering and leaving an exam room.
- Before entering and leaving SCCA or Seattle Children's.
- Before and after getting on a shuttle.

### **How to wash hands with soap and water**

It may sound a bit funny, but washing your hands properly is important. Read through the steps and practice them. Make this process a habit.

- Wet your hands with warm water and apply soap.
- Lather your hands by rubbing them together with the soap. Be sure to lather the backs of your hands, between your fingers, and under your nails.
- Scrub your hands for 15 to 20 seconds—about the time it takes to hum the "Happy Birthday" song from beginning to end twice.
- Rinse your hands with water.
- Dry your hands with a clean or disposable towel or air dryer.
- If possible, use a towel to turn off the faucet.

### **How to apply hand sanitizer (hand gel)**

- Apply one to two pumps of hand sanitizer to the palm of one hand.
- Rub your hands together.
- Rub the product over all surfaces of your hands and fingers until your hands are dry. Make sure you get the product between your fingers and on the back of your hands.
- 

### **Cleaning**

At least once a week and as needed, clean the kitchen and bathroom with a bleach solution. Make the solution daily with one part bleach to ten parts water. The solution needs to be made daily to make sure that the bleach solution is effective. You can also buy a pre-made bleach solution, such as "Clean-Up Cleaner with Bleach" spray made by Clorox®. Key kitchen areas to clean are:

- Sinks, which can be very dirty because grime and mold often stick to their surfaces
- Faucets and faucet handles
- Countertops
- Cutting boards
- Refrigerator and microwave handles
- Stovetops
- All areas that hands have touched or where food has been prepped

## **Personal hygiene**

Personal hygiene is necessary to help prevent infection. Your child may shower or bathe daily, as long as you don't submerge his or her central venous catheter under water. Details on central line care are provided later in this manual. Cover the line as instructed. Daily cleansing with soap and water is the first line of defense against bacteria on the skin.

## **Ill family members**

Your child should not be in the same home as an ill family member.

## **Dental care**

To prevent infection, daily oral (mouth) care is needed. Keep your child's mouth clean by brushing his or her teeth twice each day with toothpaste. Ask your doctor or nurse if it's okay to gently floss their teeth. Tell them if your child's gums bleed or if he has new sores in his mouth. Your nurse may give you a special mouthwash to help clean your child's mouth. Most patients who are going through a transplant see a dental specialist; ask them any questions you have about your child's dental hardware (dentures, bridges, retainers) or issues you have with oral care.

## **Safe eating**

Both how you prepare your food and what you eat play a role in keeping you healthy. Your doctor and dietitian may provide a special diet to follow depending on your child's situation. Your child might need more protein or calories or might need to avoid certain foods such as fresh produce. Follow that diet and these other tips to prevent infections:

- Do not allow your child to share cups, glasses, or eating utensils with other people.
- Cook food thoroughly. Leftovers should be stored in small containers and refrigerated within 2 hours of cooking. Reheat leftovers thoroughly.
- Keep food at its proper temperature. Keep hot foods hot and cold foods cold.
- Avoid salad bars, buffets, deli counters, and food in bulk bins.
- Avoid using ice machines in locations outside of SCCA, UW Medical Center, or Seattle Children's.
- Follow recommendations and check the guidelines for dietary restrictions.
- Ask your nutritionist questions if you don't know if something your child is eating is safe.
- Keep foods fresh and buy in small amounts to avoid spoilage and mold contamination if possible.
- Do not allow your child to eat or drink foods that are beyond their expiration date.

## **Prevent infection by having your child avoid the following:**

- **Certain activities:**

Avoid activities such as gardening, raking, mowing, farming, or direct contact with soil and plants. These activities create plant or soil aerosols which increases exposure to fungi and bacteria. Potted plants should be avoided. Your child should avoid working in green houses or managing plants at home.

- **Flowers and plants:**

Ask friends and visitors to avoid bringing fresh flowers and potted plants as gifts following your child's transplant. The organisms that may grow in water, dirt, and on plants can cause infections. After the immediate post-transplant period, you may have plants in your home, but you are discouraged from allowing your child to touch them.

- **People who have respiratory illnesses (cough, cold, and other illness):**

Be especially careful around school-aged children and those that attend daycare, since they are often exposed to other children who are ill.

- Should not be in the same home as someone with a respiratory virus.
- Avoid crowded areas where you are unable to control the distance between you and others, such as at movie theaters or sporting events.
- Construction sites, including homes or buildings that are being repaired or remodeled. These dusty environments increase your exposure to molds.
- Tobacco and marijuana use. The use of these substances, along with exposure to environmental tobacco smoke (second-hand smoke), increases your risk for bacterial and fungal infections.
- Wood-burning fireplaces, because wood contains fungus. If a wood stove is your only source of heat, have someone else touch the wood and manage the fire.
- House cleaning that will disturb dust and mold, causing it to be stirred up in the air (such as vacuum cleaning, dusting, and scrubbing down showers). If cleaning needs to be done, it is best to clean when you are not in the home, and use a wet washcloths or wipes as they capture dust. Do not use feather dusters. Once you have the energy, it is not harmful to iron, wash clothes, dry clothes, and wash dishes.
- Use of room humidifier because of bacteria that live in water.
- If you like to use air conditioners (AC) and fans during warm weather, they should be cared for properly as they can bring dust and mold into your home. Regular inspection and cleaning of the AC unit is critical. AC Filters should be changed regularly per manufacturer recommendations.
- Swimming in recreational water such as ponds, swimming pools, lakes, whirlpools, and hot tubs.
- Changing a baby's diaper.
- Touching bird droppings.
- Cleaning a fish tank.
- Emptying and cleaning litter boxes.
- Cleaning up after pets.
- Your child may feel "safer" wearing a mask when you are outside, but you are not required to wear a mask when you go out. This is a personal choice. If your child chooses to wear a mask, you should still avoid situations as described above.

## **Prevent infections spread from animals**

Have your child wash their hands immediately after petting their animals. It is not necessary to part with pets. Your child should delegate the majority of pet care to other family members or friends. It is important to minimize direct contact with animals, especially animals that are ill, and avoid getting any new pets during your child's transplant. Do not allow your child to sleep with pets.

If you have a cat, do not place the litter box in kitchens, dining rooms, or other areas where food preparation and eating occur. Have someone else handle the daily litter box cleaning during the first year after transplant and when your child is on immunosuppressive medicines. This will reduce your child's risk of acquiring toxoplasmosis, a parasitic disease. Keep your cats inside and do not adopt or handle stray cats.

It is recommended to avoid contact with reptiles (turtles, snakes, lizards), ducklings, or chicks to prevent exposure to bacteria called salmonella. If you have other pets, please discuss this with your team.

## **Vaccinations**

It is beneficial for family members and household contacts to be vaccinated to prevent exposure to vaccine-preventable diseases. Recommended vaccines help to prevent important diseases such as influenza (flu), pertussis (whooping cough), measles, mumps, rubella, chicken pox, tetanus, diphtheria, and pneumococcal. Have your family members, caregivers, and close contacts see their doctors to make sure they are up to date on all of the recommended adult vaccines. Children should also be up to date on all childhood vaccines.

Some vaccines, such as MMR (measles, mumps, and rubella), varicella (chicken pox), and shingles (Zostavax<sup>®</sup>) vaccines are live-virus vaccines. It is often safe for persons in your household to receive these, but make sure you discuss the timing of these vaccinations for your family members with your child's care team. Some of these live vaccines pose a very small risk of household transmission, so if a family or household member develops a rash after receiving the chicken pox or shingles vaccine, notify your doctor or nurse.

It is very important that family members and household contacts receive the flu (influenza) shot every year. The flu vaccine is the best way to prevent the flu. SCCA offers the flu vaccine to family and household contacts. If your family or household contacts opt to receive the nasal spray flu vaccine (Flumist<sup>®</sup>), have your child avoid contact with that person for five days, as the nasal spray vaccine contains a weakened live flu virus that could spread to your child.

Recent outbreaks of pertussis have been seen throughout the U.S., including Washington State. Due to the risk of pertussis (also known as whooping cough) in transplant patients, make sure that your family, caregivers, and visitors check with their doctor to see if they are up to date on this vaccine (also known as Tdap – tetanus, diphtheria, and pertussis).

Be sure to notify your team if you have been exposed to an infection, if your caregiver or family member is ill, or if they have recently been diagnosed with an infection.

## **How does the clinic work to prevent infections?**

Infection prevention is a very high priority at SCCA and a foundation of preventing major post-transplant complications. All infections cannot be avoided, but here are some of the steps taken in order to ensure that your child receives care in a safe environment:

- All staff cleans their hands while performing patient care. If you would like to confirm that the staff caring for your child has cleaned their hands, we encourage you to ask them. Staff know that we all need to work together to prevent infections. By asking, you are helping us maintain a high standard of care.
- Isolation precautions are used as a way of stopping the spread of germs from one person to another. Your child may be placed on isolation if he or she has an infection that can be transmitted or harmful to other people. If your child is in isolation, staff will take extra precautions to ensure that those germs

do not spread. Staff may place your child in an exam room right away, clean their hands more often, and wear protective equipment, like gowns, gloves, and masks. If your child is in isolation, make sure to remind staff when you arrive at SCCA or are admitted to the hospital.

- We take cold and flu season very seriously. When you check-in for your appointments, at certain times of the year you and your family or caregiver may be asked if you have cold or flu symptoms like a cough or runny nose. If you do not have symptoms of cold or flu, you will be given a sticker to wear that indicates that you have been screened. If you have symptoms, you will be given a mask to wear and you will be placed in isolation to prevent the spread of cold and flu viruses.
- You may notice patients wearing masks. Patients with cold and flu symptoms are encouraged to wear a mask while walking through SCCA. This helps to prevent the spread of cold and flu viruses.
- If you have a cold or the flu, it is especially important that your child avoid riding any of the shuttles. Let your team know and your nurse will give you taxicab vouchers to use until your cold and flu symptoms go away.
- The flu vaccine is provided to caregivers and household members of transplant patients. Information about flu vaccine clinics are posted starting in October yearly.

#### **References**

Preventing Infections in Cancer Patients. Centers for Disease Control and Prevention (CDC). [www.cdc.gov/cancer/preventinfections](http://www.cdc.gov/cancer/preventinfections) Accessed 2/21/2014.

What are the risks of a blood and marrow stem cell transplant? National Heart Lung and Blood Institute [www.nhlbi.nih.gov/health/health-topics/topics/bmsct/risks.html](http://www.nhlbi.nih.gov/health/health-topics/topics/bmsct/risks.html) Accessed 2/21/2014

Protecting Yourself from Infection. National Marrow Donor Program. <http://bethematch.org/For-Patients-and-Families/Life-after-transplant/Staying-healthy/Infection-prevention/> Accessed 2/21/2014

# Anemia

## Just the facts

Red blood cells carry oxygen to the tissues of the body. Hemoglobin and hematocrit are the tests used to evaluate the red blood cell count. When these measures are low, your body tissues do not get enough oxygen to do their work. If red blood cells are low, this condition is called anemia.

## Your goals

- Recognize your child's symptoms early.
- Get professional help when needed.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Dizziness.
- Shortness of breath.
- Unusually tired or weak.
- Pounding head or ringing in your child's ears.

## What your child can do at home

- Get plenty of sleep.
- Save energy by resting between short periods of activity.
- To avoid getting dizzy, your child should move slowly when getting up from a lying position and sit up for several minutes before standing.
- Add green leafy vegetables and liver to your child's diet when possible.

Information adapted from: Pharmacia and Upjohn Company

# Anxiety

## Just the facts

It is very common for a person to feel anxious when facing a new or stressful situation. We all feel worried at times in our day-to-day lives. Your child may experience anxiety as nervousness, tension, panic, fear, or feeling like something bad is going to happen. Anxiety can also be experienced as physical symptoms such as upset stomach, sweaty palms, and fast heartbeat, shaking or flushed face.

Although it is normal to feel anxious when facing a life-threatening illness and intensive treatment, there are things that may help decrease the feelings of anxiety. The goal is to reduce anxiety, not eliminate all anxiety.

## Goals

- Learn how to cope with anxiety.
- Get professional help when needed.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Feelings of dread and apprehension for several days.
- Physical symptoms such as sweaty palms, shaking, rapid heartbeat, etc. Keep in mind that these symptoms can be side effects of treatment.
- Wide mood swings that you cannot control.

## What you and your child can do at home

Learn how to cope with anxiety.

- Recognize that anxiety during treatment is normal and so is getting help for it.
- Try to understand what thoughts are triggering the anxiety. For example, if your child is anxious about a medical procedure, ask him what it is about the procedure that is upsetting. Staff may be able to assist and help you find ways to cope with your child's anxiety.
- Getting the facts can help. For example, if you are worried about your child's pain or discomfort, there is information available on how to manage symptoms and side effects.
- Thinking about doing things that are pleasant and relaxing can help reduce anxiety. Relaxation is a skill that can be used to counteract anxiety.

## Get professional help when needed

If anxiety doesn't improve despite efforts to reduce it, discuss it with your doctor, nurse, or social worker.

# Bleeding

## Just the facts

Chemotherapy slows the production of platelets. Platelets help the blood to clot and stop flowing if there is an injury. Bleeding problems can be triggered by certain medications, injuries, vigorous exercise, or deep massage when your child's platelet count is low.

## Goals

- Prevent bleeding.
- Control bleeding if it starts.
- Call for professional help when needed.

## Emergency signs and symptoms

Call 911 **immediately** if:

- Uncontrolled, constant bleeding.
- Patient is unconscious.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **now** if:

- New or increased bleeding or bruising.
- Bloody urine.
- Little red or purple spots on the skin.
- Unable to stop nosebleed.
- Bloody diarrhea.
- Vomiting of blood.
- Patient falls or is injured.
- One or more feminine pads per hour are used.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Little red or purple spots on the skin or in the mouth.
- New bruising.

## What you can do at home for your child

Prevent bleeding

- **Do not take or give over-the-counter medications** without first consulting your doctor, nurse or pharmacist. Certain medications can increase your child's risk of bleeding. Do not take aspirin, ibuprofen, naproxen (Aleve®), Alka-Seltzer®, or cold remedies containing these drugs. Talk to your doctor or nurse before giving your child any over-the-counter medications. This is only a partial list of medications that can affect your child's platelets.
- Take blood pressure medications as ordered; high blood pressure can trigger bleeding.
- Use a soft bristle toothbrush.
- Do not use razorblades; use electric razors for shaving.
- Use caution to avoid falls.
- No vigorous exercise; follow activity guidelines from physical therapist or doctor.

- Do not engage in deep massage.
- Do not blow nose hard or scratch inside of nose.
- Women who are menstruating should use pads, not tampons.
- Women are not to resume sexual intercourse if they have experienced breakthrough bleeding (any vaginal bleeding) within 2 weeks.
- No anal sex until platelets are stable.
- No rectal insertion of suppositories, enemas, or thermometers.

### **Control bleeding if it starts**

- Apply pressure to the bleeding site. For example, for a nosebleed, press the nostrils together firmly with the fingers. Or wrap ice in a soft cloth and press it firmly against the nostrils.
- Hold pressure on bleeding site for a full 5 minutes before checking to see if bleeding has stopped.
- Remain calm.

### **Call for professional help when needed**

- If a nosebleed doesn't stop after 30 minutes of applying pressure, contact your care team.
- When transporting a patient with a bleeding problem, keep pressure on the bleeding site. Keep the patient quiet and minimize activity.

# Body image changes

## Just the facts

Treatment can affect your child's body and life in ways that may be hard on your child's self-esteem. Weight loss or gain, loss of stamina, skin reactions, and a puffy face - all of these can be distressing if your child thinks of their body as being who they are. Fortunately, most of the side effects of therapy, which affect appearance and stamina, are temporary.

The first step in coping with body changes is to direct your child's energy and thoughts toward what they can control. Paying attention to skin care, diet, exercise, and positive attitudes are healthy ways to cope with body image changes. Finding ways for your child to express his or her feelings about the changes is very important.

## Goals

- Maintain a confident and positive self-image.
- Take care of skin.
- Build stamina with exercise.
- Wear attractive and comfortable clothing.
- Get professional help if needed.

## Important signs and symptoms

- Report symptoms to a doctor or nurse during clinic hours today.
- Feeling or acting very sad most of the day, very angry, or losing interest in life because of body changes.
- Not taking care of self (not exercising, dressing, or caring for skin).

## What your child can do at home

- Maintain a confident and positive self-image.
- Encourage your child to express feelings to trusted family members, friends, doctor, nurse, or social worker.
- Talk with other people who have had similar treatment about what they did and how they coped with changes in body image.
- List your best points, and then list your options on how you would like to try to maintain a good body image.
- Laugh! Humor is a fine way to cope. Treat your child to funny movies, TV shows, books, or even people.

## Consider using a hair alternative

- Buy or borrow a wig. The Patient and Family Resource Center on the 3<sup>rd</sup> floor of SCCA offers wig fitting appointments and wig resources. Most offices of the American Cancer Society can tell you how to obtain or borrow a wig. Many of them have a "wig bank."
- Use a headwrap. Making headwraps out of scarves is easy. A headwrap can complement your looks. The emphasis should be on color and texture rather than on complicated tying techniques.
- The book *Beauty and Cancer* by Diane Doan Noyes and Peggy Mellody, gives instructions on headwraps, skin care, makeup, clothing, nutrition, and exercise.

- Try turbans, scarves, hats, or caps. Head coverings protect against drafts, enhance appearance, and help retain body heat.

### **Your child can wear attractive and comfortable clothing**

- Wear colorful clothing. Chemotherapy and radiation tend to make skin pale, sallow or ruddy. Colors and interesting patterns can decrease the intensity of skin changes.
- If your child's face becomes very round or puffy, wear a "V" shaped neckline.
- If your child has lost a lot of weight, try a round or oval neckline.
- Avoid any garment that might puncture or break the central intravenous line such as front clasping underwire bras or pins. Soft fabrics drape best over catheters.

### **Take care of your child's skin**

- Select skin care products that your child likes and are inexpensive, fragrance-free, hypoallergenic and alcohol-free.
- Cleanse skin twice a day. Mild soap and water is the most basic cleanser, especially good for oily skin. Cleansing creams are good for dry and normal skin because of their moisturizing effect. All cleansing products should be applied gently to avoid pulling the delicate surface of your skin. Use caution to avoid bruising the skin.
- Use a moisturizer to help skin retain its moisture. Avoid hot water.
- Wear sunscreen or protective clothing when outside.
- Report any skin changes such as rash or inflammation to the doctor or nurse.

### **Build stamina with exercise**

- Exercise daily. Exercise is one of the simplest and most effective ways to reduce stress, increase stamina, and impart a feeling of well-being.
- Begin slowly with low intensity exercise, such as walking. Your child's body will tell her what her limits are. A good rule of thumb is your child should never be out of breath. Your child should be able to talk while exercising.

### **Get professional help**

Talk with your child's doctor, nurse, or social worker for a referral to a counselor.

# Breathing problems

## Just the facts

Difficulty breathing may occur during your child's treatment. Symptoms include shortness of breath, wheezing, and cough. A number of things can cause breathing problems: infection in the lungs, fluid in the lungs, or bleeding. The most common cause is infection. Do everything you can to prevent irritation and infection in the lungs. Exercise and breathing clean air helps the lungs function optimally.

## Goals

- Keep your child's lungs healthy.
- Call for professional help when needed.

## Emergency signs and symptoms

Call 911 **immediately** if your child is:

- Unable to breathe.
- Choking/not able to move air.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **now** if your child:

- Trouble breathing/shortness of breath.
- Gets "winded" more easily with normal activity.
- Feeling as if they can't get enough air.
- Troubled breathing when lying flat.
- Wheezing with breaths.
- New or recurrent cough.
- Uncontrollable or continuous cough.
- Tightness or wheezing with each breath.
- Coughing blood or green/yellow sputum.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today:

- New or recurrent cough.
- Gets "winded" more easily with minimal activity.

## What your child can do at home

Keep lungs healthy:

- Avoid smoke or being around smoke.
- Exercise daily. This helps expand the lungs and improves oxygen exchange and blood flow.
- Sitting in an upright position allows the lungs expand and exchange oxygen better. For example, during the day, sitting is better than lying flat. Standing up and moving really let the lungs expand.
- Avoid any clothing that restricts breathing.
- Avoid contact with any person who has signs of respiratory infection (cold, fever, sneezing, runny nose, etc.).
- Call for help right away when your child has a problem with breathing. The sooner treatment can be started, the more likely the treatment will work.

# Change and uncertainty

## Just the facts

The treatment process is one filled with changes and uncertainty. When will this be done or how can a family plan ahead? Answers to these questions are difficult because each patient responds differently to treatment. Complications are hard to predict. Take it day by day.

## Goals

- Adapt to change.
- Cope with uncertainty.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today if your child is having:

- Feelings of dread and apprehension for several days.
- Physical symptoms such as sweaty palms, shaking, rapid heartbeat, and so on. Keep in mind that these symptoms can also be caused by side effects of treatment.
- Wide mood swings that your child cannot control.

## What you and your child can do at home

Adapt to change:

- Identify the change that is taking place and any options you have.
- Discuss these changes with family and staff.
- Ask staff for explanations.
- Keep track of questions and information in a notebook.

## Cope with uncertainty

- When planning for the future, limit the time span as much as possible.
- If plans need to be made, consider alternative plans.
- Encourage your child to talk with someone who listens about their hopes and disappointments.

# Constipation

## Just the facts

It is common for a person with cancer to develop constipation, especially when opioids (narcotics) are being used. Bowel movements can become infrequent, hard, and small in volume. It is important to avoid letting this become a problem.

Constipation can develop because of inactivity, some pain medications, changes in the body, lack of fluids/fiber, and depression. Excessive use of laxatives can make the colon less sensitive to its natural reflexes, so always discuss use of laxatives with your doctor or nurse.

## Goals

- Prevent constipation and recognize symptoms early.
- Get professional help when needed.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today:

- Bloating abdomen and/or abdominal pain.
- No bowel movement for more than 2 to 3 days.
- Dizziness and/or confusion.
- Back pain.
- Leaking stool.
- Fever.
- No bowel movements with nausea and vomiting.

## What you and your child can do at home

Preventing constipation:

- Drink plenty of fluids. Drinking hot water upon rising in the morning can stimulate the bowels.
- Eat food that is high in fiber when possible. Fiber includes: fruits, figs, dates, prunes or prune juice, vegetables, and grains. Ask your nurse if you would like a consultation with the dietitian.
- If your child is taking pain medication, ask your doctor or nurse about the use of laxatives and stool softeners.
- Keep your child as physically active as possible.

Ask your doctor or nurse if your child needs a laxative.

# Dehydration

## Just the facts

Dehydration means there is not enough fluid in your child's body. It occurs when there is not enough fluid intake. The body does not function well without enough fluid. Excessive loss of fluid can result from diarrhea, vomiting, fevers, and sweating. Dehydration can cause complications such as increased weakness, dizziness, rapid heartbeat, and confusion.

## Goals

- Fluid intake.
- Call for professional help when needed.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **immediately** if your child is:

- Dizzy or lightheaded.
- Fainting.
- Confused.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Decreased urination, dark urine, strong smelling urine.
- Increased weakness.
- Decrease in eating and drinking.
- New or increased vomiting.

## What you and your child can do at home

- Promote fluid intake. Drink as many liquids as possible. If you detect early signs of dehydration in your child, have him drink more.
- Avoid caffeinated beverages such as: coffee, cola, diet cola, hot or iced tea, and hot chocolate.
- Check with the dietitian or nurse for goals or restrictions.

## Get professional help when needed

- Monitor for signs of dehydration such as decreased amounts of urine and dark urine.
- Report symptoms to the doctor or nurse promptly.

# Depression

## Just the facts

Dealing with a life-threatening illness causes a roller coaster of emotions. Most patients experience feelings such as helplessness, despair, and sadness during treatment. Symptoms of depression can also include loss of appetite, changes in sleep patterns, lack of energy, and inability to focus. If your child has had symptoms of depression or have been on anti-depressants before, be sure to inform the doctor, nurse, or social worker.

## Goals

- Acknowledge that it is normal to have feelings of sadness at times.
- Allow your child to feel sad at times.
- Identify when your child needs help with depression.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Feeling sad most of the time for several days.
- Feelings interfere with your child's ability to care for herself.
- Your child has thoughts about hurting himself.
- Mood swings that your child cannot control.

## What you and your child can do at home

- Allow you and your child to feel sad at times.
- Talk about these feelings with someone who listens (family member, social worker).
- Talk with other patients in your situation (support groups, phone contact, Internet).
- Use spiritual resources.

## Get professional help when needed

Psychiatrist and psychologists can provide:

- Evaluation of cause of depression (sometimes medications can cause depression).
- Medication to manage depression.
- Counseling.

Ask your doctor, nurse, or social worker for a referral.

# Diarrhea

## Just the facts

Diarrhea is frequent bowel movements with the stools having a more or less fluid consistency. Diarrhea is caused by chemotherapy, radiation, medications, and sometimes emotional distress. It is important to report diarrhea because it can lead to dehydration and loss of electrolytes. It is not always possible to prevent diarrhea.

## Goals

- Prevent dehydration.
- Prevent infection.
- Call for professional help when needed.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **now** if your child is experiencing:

- Constant or uncontrolled diarrhea.
- New onset of diarrhea.
- Fever and abdominal stomach cramping.
- Whole pills passed in stool.
- More than 5 bowel movements a day.
- Stool that is bloody, burgundy, or black.
- Abdominal cramping.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today:

- New onset of diarrhea.
- Diarrhea more than 5 times a day.
- Mild abdominal stomach cramping.
- Whole pills passed in the stool.

## What you and your child can do at home

Prevent dehydration:

- Drink fluids (in suggested amounts).
- Follow dietary recommendations. Note any food allergies or intolerances and discuss with the doctor, nurse, or dietitian.
- Prevent infection and irritation.
- Wash hands often with soap and warm water.
- Keep anal area clean with mild soap and water.
- Do not use ointment or creams on the anal area unless directed by your care team.
- Use white, non-perfumed toilet paper.

## Call for professional help when needed

- Describe the type of diarrhea to health care staff by including frequency, consistency, color, and presence of cramping.

## Exercise and blood value precautions

**Platelets** are parts of your blood that are important for blood clotting. Your child's platelet count must be greater than 20,000 before he or she can do any type of cardiovascular exercise or strength training with weights (cuff weights, dumbbells, machines, and elastic tubing). If your child's platelet count is consistently below 100,000, you need to check his blood counts before exercising to know whether or not you he can do strength training and/or cardiovascular exercise. If your child's platelet count is less than 20,000, you may have an increased risk of bleeding with certain types of exercise that could become serious and even life threatening.

- **Platelet count 50,000 to 100,000:** cardiovascular exercise and strength training with weights are allowed. If your child has any signs of bleeding (such as from the nose), your child should **not** exercise, and you must notify your physician or care team, even if your child's platelets are in this range.
- **Platelet count 20,000 to 49,999:** strength training with weights and cardiovascular exercise are ok if your child has no signs of bleeding, but exercise must be performed without strain, such as holding your breath. Strain during exercise can spike your blood pressure and increase your child's risk for a stroke or major bleed. Massage at this platelet count should be discussed on a case-by-case basis with your physician. Gentle comfort massage is allowed if the skin is not fragile or prone to easy bruising for other reasons (such as chronic steroid medications), but deep tissue massage is **not** allowed.
- **Platelet count 10,000 to 19,999:** strength training **without** weights (machines, dumbbells, or elastic tubing), and cardiovascular exercise **without** strain, are both ok when your child is steady on his feet and has no sign of bleeding.
- **Platelet count less than 10,000:** **no** strength training or cardiovascular exercise until your child's platelet count is in a safe range for exercise. Walking around his room and to the bathroom is ok as long as your child is steady on his feet and has no sign of bleeding.

**Hematocrit (Hct) and hemoglobin (Hgb)** are lab values that reflect the level of red blood cells within your blood. Red blood cells carry oxygen around to your tissues. If your child's red blood cell number and oxygen-carrying capacity (Hct and Hgb) are too low and your child exercises anyway, he is diverting needed oxygen from his vital organs to his muscles, which may cause micro-damage to his organs. When your child's Hct or Hgb are too low, your child is not allowed to perform strength training or cardiovascular exercise until he has had a red blood cell transfusion and we are sure that his red cell numbers have improved to the safe range. It's always difficult to anticipate how much a transfusion will increase the level of Hct and Hgb – a follow-up blood count is the only way to know for sure.

- If your child's hematocrit is less than 25% or hemoglobin is less than 8.0, it is necessary to consult with your doctor or a physical therapist to determine safe exercise options.

# Fall prevention

## Just the facts

Your child may be at risk for falls because of:

- Different environments than your child is used to.
- Medications that make your child tired, dizzy, or confused.
- Weak muscles from taking steroid medications.
- Low red blood cells or a low blood pressure that could make your child dizzy.

If your child has a history of confusion with any medications for nausea or pain control, let your doctor or nurse know. We want to prevent falls both in the clinic and at home. Review this information with family members and friends who are part of the team to keep your child safe.

## Goals

- Prevent injury.
- Prevent permanent disability.
- Prevent death.

## Emergency signs and symptoms

Call 911 **immediately** at home if:

- Your child fell and is bleeding.
- Any loss of consciousness occurs.
- You think your child has a broken bone.
- Your child has fallen and hit her head, has low platelets, and/or is on anti-coagulant medications.

Do not attempt to get your child up alone, because you might hurt yourself or your child.

## Important signs and symptoms

Report symptoms to your doctor or nurse during clinic hours today:

- If your child has fallen, even if you think that nothing is wrong.

## What you and your child can do at the clinic

- **Wear safe shoes!** This is one of the most important things you can do to prevent falls while your child is here. Our floors can be very slippery. Closed-toe, closed-heel shoes with non-skid soles are the best choice (like tennis shoes). Flip-flops or open sandals are very dangerous. It is OK with us if your child puts her shoes on our exam tables and beds so that her shoes are always on to keep her safe. We don't want your child to **ever** walk around in socks or with bare feet. Non-skid slippers are available if she forgot her good shoes. Please ask for a pair.
- **Ask for help.** It does not bother the staff for you or your child to ask for help. Even if your child gets around at home by herself, your child might need extra help while she is in our clinic. We can help her get from one place to another in our clinic, get on an exam table, or walk her to the bathroom.
- **Move around with care.** Be careful that you and your child don't lean on wheeled equipment for support. Wheelchairs are available to use in the clinic.
- **Get up slowly after treatments and procedures.** Have your child wait to see if she feels dizzy or weak. She might need help from a staff person.

- **Use assistive devices.** If your child uses a hearing aid, glasses, prosthesis, or walker/cane, be sure to bring it to the clinic and use it while she is here.

If you see anything that is hazardous in the clinic (like a spill on the floor), tell staff right away.

### **Call for professional help when needed if your child**

- Is groggy, dizzy, or feeling faint.
- Has fallen, let staff know **right away** by yelling or asking anyone around you to help.
- Do **not** attempt to get your child up alone. You might hurt yourself or your child trying to get her up.

### **What you and your child can do at home**

- Think about the shoes your child wears. Have your child avoid wearing shoes such as slippery slippers or socks, high heels, shoes without backs, or flip-flops. Wear sturdy, non-skid shoes such as tennis shoes. Wear them inside and outside the house. Avoid going barefoot, even inside the house.
- Move furniture so there are clear paths.
- Keep the floor, pathways, and stairs clear of objects. Remove things your child can trip over (like paper, books, clothes, and shoes) from stairs and halls.
- Never put small objects inside/outside your house, especially on the stairs.
- Fix loose or uneven steps.
- Have sturdy handrails and lights in all stairwells/staircase areas. Make sure carpet on the stairs is attached firmly to every step.
- Consider using reflective tape at the top and bottom of stairs.
- Tape cords and wires to the floor/wall away from the walking path.
- Remove small throw rugs or use double-sided tape to keep the rugs from slipping.
- Enhance/add to the existing lighting home. Hang lightweight curtains or shades to reduce glare.
- Place a lamp next to your bed within easy reach and turn on the light when getting out of bed.
- Install nightlights all the way to the bathroom (bedroom, hallways, and bathroom).
- Put a non-slip mat in the bathtub and on shower floors.
- Consider installing a grab bar in the bathtub, shower, and near the toilet.
- If your child has balance problems, consider having him use a shower seat or urinal for showering and dressing.
- Keep items that are used often in cabinets and on shelves that are within easy reach, without use of a step stool.
- Never stand on a chair.
- Get up slowly after sitting up or lying down.
- Consider painting doorsills and other flooring level changes a different color so your child doesn't trip.
- Review medications regularly with your doctors to identify medicines that cause sleepiness, dizziness, or confusion so your child can be extra-safe after taking these medicines.
- Don't drink alcohol if taking sedating medications.
- Talk to your child's doctor about seeing a physical therapist for mobility aid and balance and strengthening. Practice approved exercises regularly to improve strength, balance, and coordination.

#### **References:**

Holly, S. (2002). A Look at the Problem of Falls Among People with Cancer, Clinical Journal of Oncology Nursing  
 Rao, S.S. (2005). How to Prevent Falling, American Family Physician ©Seattle Cancer Care Alliance, 2005  
 Rao, S.S. (2005). How to Prevent Falling, American Family Physician

# Fatigue

## Just the facts

Being tired is a very common experience for patients. Fatigue is a daily lack of energy, an unusual or excessive whole body tiredness not relieved by sleep. There are a number of possible causes for fatigue: the intensive treatments, medications, a lower than normal number of circulating red blood cells, stress, decreased nutrition, nausea, vomiting, mouth sores, taste changes, heart burn, diarrhea, disruption of normal resting and sleep habits, or feelings of depression. It usually takes time to work out ways to live with fatigue.

## Goals

- Establish regular rest and sleep periods.
- Conserve energy.
- Get professional help when needed.

## Emergency signs and symptoms

Call 911 **immediately** if:

- You are the caregiver and cannot wake your patient.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **now** if your child is:

- Dizzy.
- Too tired to get out of bed or walk to the bathroom.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Fatigue is getting worse.
- Staying in bed all day.
- Other symptoms occur with increased fatigue.
- Increased weakness or exhaustion.
- Drowsiness or confusion.
- Loss of balance.
- Child is trying to catch his breath.

## What you can do at home

- Establish regular rest and sleep periods.
- Set up a regular daily schedule for nap and sleep times.
- Keep active during the day to sleep better at night.
- Play soft music, put on the TV as a background sound, engage in meditation or prayer, or offer your child a back rub to help them sleep or rest.
- Keep a diary for one week to monitor fatigue levels. Note what you think may be contributing factors.

**Conserve energy**

- Rest between bathing, treatments, and exercise.
- Do things or be active only for a short time.
- Plan activities such as exercise, visits, or trips when feeling the most rested and energetic.
- Decide on the most important activities for the day. Be realistic.
- Regular exercise helps reduce fatigue; it sounds contradictory, but it helps.
- Give your child snacks between meals to keep up his energy.
- Plan ahead and organize your work.

# Fever

## Just the facts

Seek professional help when your child has a fever. A fever and chills are signs of possible infection. A patient is very vulnerable to infection after chemotherapy, radiation, while on immunosuppressive medications, and when blood counts are low. Act promptly when a fever occurs because the your child cannot fight infection when her number of white blood cells is low.

## Goals

- Monitor the your child's temperature.
- Seek professional help when your child has a fever.

## Urgent signs and symptoms

Go to ***Seattle Children's Hospital Emergency Department (ED) NOW if:***

- Temperature taken by mouth is between 38 to 38.2°C (100.4 to 100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above.
- Temperature taken under the arm between 37.5 to 37.7°C (99.5 to 99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above.
- Fever greater than 1 degree above normal when the patient is on prednisone or steroids.
- Shaking chills (temperature may be normal).
- Cold symptoms (runny nose, watery eyes, sneezing, coughing).
- Note: Do not give Tylenol® (unless directed by the doctor or nurse).

**If your child has a fever you may be directed go to the Seattle Children's Emergency Department (ED). For timely care and service at the ED, please follow these steps:**

1. If your child has a fever, always call the BMT team (SCCA or inpatient BMT provider) before you go to the ED.
2. Keep your child warm and comfortable when transporting them if they have chills.
3. The ED will expect a call from the BMT provider with information about your child's case.
4. The lobby nurse will be informed that your child is on their way to the ED.
5. As soon as you arrive at the ED your child will be registered and checked in by the lobby nurse.
6. If there is a wait line, quickly let the security guard (at the computer next to the lobby nurse) know that your child is a BMT patient.
7. The security guard will make sure that the lobby nurse puts your child at the top of the list to be seen.
8. Once checked in and brought back to a room, a plan will be followed using best practices to manage fever and possible infection in BMT patients.
9. In the rare event that your child needs advanced life support, experts in the ED can provide this.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today:

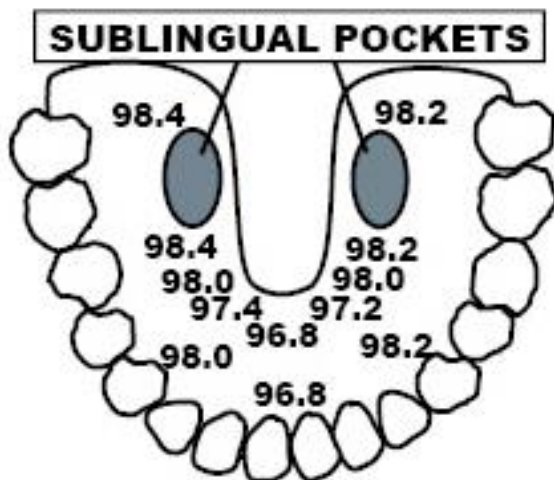
- Any new redness or swelling on the skin or at an intravenous (IV) site.
- Cold symptoms (runny nose, stuffy nose, watery eyes, sneezing, coughing).
- New abdominal or back pain.
- Toothache.
- Cloudy or foul-smelling urine. Pain with going to the bathroom.
- Sinus pain.

## What you and your child can do at home

- Monitor your child's temperature.
- Take your child's temperature twice a day, morning and evening.
- Take oral (mouth) or axillary (under the arm) temperatures only. Do not take rectal temperature as the thermometer may injure membranes inside the rectum.
- Keep a record of your child's temperature.
- Use the thermometer for your child only.
- If using a glass thermometer, wash the thermometer after each use with warm (not hot) water and soap.

## Where to take temperature

The best way to take a temperature is to place the thermometer into the mouth under the tongue in the sublingual pockets. The sublingual pockets are in the lower jaw, under the tongue (see image below). If you have any questions, please ask your care team.



# Hand-foot syndrome

## Just the facts

Hand-foot syndrome (HFS) is a side effect of certain chemotherapy drugs. HFS symptoms may be caused by the breakdown of chemicals that are used in chemotherapy. HFS is a skin reaction which often affects hands and feet, although it can also affect other areas where there is increased pressure or warmth (like the buttocks, groin, armpits, or under the breasts).

## Goals

- Avoid tight fitting shoes or gloves.
- Control skin irritations with moisturizers and avoid activities that can make HFS worse.
- Call for professional help when needed, especially if pain becomes a problem.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today:

- Palms or soles of the feet are red or tender.
- Skin of palms and soles peeling.
- Numbness, burning, or tingling sensation.

## What you and your child can do at home

Prevent dryness and irritation:

- Apply moisturizer to your child's hands and feet frequently, especially in the creases. Recommended moisturizers include: Bag Balm®, Udderly Smooth Cream®, lanolin creams (unless allergic to wool), Aveeno® cream, Eucerin® cream, and Lubriderm®.
- Avoid heat. Bathe or shower in lukewarm water. Soak hands/feet in basins of cold water for 15 minutes 3 to 4 times per day when possible. Take cool baths and put gel ice packs on affected areas.
- Avoid activities that cause irritation due to even slight rubbing or pressure on the skin. For example, vigorous washing, gripping tools, typing, driving, or playing musical instruments. Do not apply any adhesives or dressings such as Band-Aids®, since adhesive will irritate skin further.
- Sit or lie on padded surfaces of chairs or mattresses. Raise legs whenever possible with cushions.
- Place a pillow between knees or wear pajamas if rubbing of legs occur during sleep.
- Avoid any unnecessary and vigorous exercise.
- Wear loose fitting clothing and shoes with comfortable soles. Do not walk barefoot.

**Alleviate symptoms if they start**

- Place palms or bottoms of feet on an ice pack or a bag of frozen peas to provide temporary relief from pain and tenderness. Alternate on and off for 15 to 20 minutes at a time. (May use gel insoles that can be cooled before insertion in shoes).
- Apply moisturizing cream of choice after the area has been cooled for maximum comfort.
- If your doctor suggests a steroid cream, apply it after the skin has been cooled and apply moisturizers over the top of the steroid cream for maximum effectiveness.
- If blistering and ulceration starts, apply gentle moisturizers on your hands and feet and contact your doctor or nurse, who may suggest further therapies.
- Talk with your nurse about how to change your activities of daily living (bathing, dressing, and eating) if the HFS is severe.
- Contact your doctor regarding other over the counter or prescription options to relieve symptoms of HFS.

# Memory and concentration

## Just the facts

Changes in memory and concentration are common throughout treatment. The changes may be temporary. Your child's memory and concentration may improve as his treatment is completed and when he starts feeling better. Many factors affect memory.

Memory and concentration problems may be situational and vary from day to day due to stress, pain, medications, menopause, anxiety, aging, depression, and fatigue. Since your child may have good and bad days, you may want to use routine strategies to assist you when your child is having a bad day. It can be a frustrating and taxing problem.

## Goals

- Learn how to cope with changes in memory and concentration.
- Get professional help when needed. Neuropsychologists evaluate memory.
- Ask your doctor to make sure that your child's medications are not causing the problem.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **now** if your child is:

- Disoriented
- Confused

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today if your child is:

- Forgetting things more quickly and more often than usual.
- Finding it harder to read more than a paragraph or a page at a time.
- Finding it hard to keep his mind from wandering.

## What you and your child can do at home

Learn how to cope with changes in memory and concentration, you or your child can:

- Write down important information. Keep these notes on a notepad that is small enough to keep with you at all times.
- Establish consistent daily routines.
- Have regular sleep time and eat nutritious snacks and meals.
- Manage stress.
- Keep distractions to a minimum.
- Ask people to repeat things.
- Keep a list of questions for your child's doctor. Write the answers down.
- Tape record important conversations or conferences.
- Get important information in writing. Ask people to write it down for you.
- Place notes around the house to remind your child of things.
- Keep an appointment calendar and one central memory book.
- Use a device to remind your child to take your medications such as a watch or cell phone timer that can be programmed to go off at times when medications need to be taken.
- Keep regularly used items in a designated place).

- Be understanding and patient with your child and know that these temporary changes are to be expected.
- Ask your doctor to review your child's medications.

## How to keep minds active

Below is a list of resources you might want to utilize to enhance your child's cognitive abilities. There are things you can do to regain some of your child's mental plasticity and prevent any further decline in cognitive faculties.

- **Puzzle books:** Crossword puzzles are known to improve mental skills.
- **Sudoku:** Similar to a crossword puzzle, but with numbers instead.
- **Card games:**
  - Start with a shuffled deck of cards and a stopwatch. Sort the cards into separate piles, one for each suit (diamonds, clubs, spades, hearts). Do this three times daily. A typical young adult can do this in 35 seconds. Keep practicing this task until you can do it in that amount of time!
  - Play and learn other card games such as bridge, rummy, pinochle, canasta, cribbage, black jack, or solitaire.
- **Games:** Play stimulating games such as chess, checkers, Scrabble®, and any other games your child enjoys. If your child has a Nintendo®, try the game Brain Age, developed by neuroscience researchers to improve mental abilities and hand/eye coordination.
- **Hobbies:** Learn a new skill such as knitting or crocheting, or a new sport. Have your child try writing and brushing her teeth with the opposite hand than she usually does.
- **Conversation:** Enjoy a conversation with a friend and discuss world events.
- **Languages:** Learn a new language. Rosetta Stone® has CDs that you can purchase in various languages.
- **Read books:** Join a book club, or attend a book reading. A couple of suggestions include:
  - *The Better Brain Book* by David Perlmutter and Carol Colman
  - *Whole Brain Thinking* by Jacquelyn Wonder and Priscilla Donovan
  - *Carved in Sand* by Cathryn Jakobson Ramin (the story of her struggle with early onset memory loss).
- **Website suggestion:** [www.positscience.com/](http://www.positscience.com/) is a website where you can try out a couple of the exercises from their Brain Fitness Program. This program has been used to help veterans with traumatic brain injuries recover some of their capabilities.

## Get professional help when needed

If problems persist or affect day-to-day living to a large degree, discuss the symptoms with your doctor or nurse. Ask your doctor or nurse about a neuropsychological referral and neuro-rehabilitation treatment.

# Mucositis (inflammation of mucous membranes)

## Just the facts

Mucositis and mouth pain are common physical problems for chemotherapy and radiation patients. Chemotherapy and radiation lead to inflammation of cells of the tongue, lips, mouth, throat, and gastrointestinal tract. Saliva usually becomes thicker and more mucous-like. Mouth sores or bleeding in the mouth may occur also. The experience varies from mild discomfort to severe pain, which makes eating, drinking, and sleeping difficult.

Your child's ability to fight infection is temporarily reduced by the therapy (chemotherapy and/or radiation). The inflamed mouth is a possible site of infection. Swelling may make it hard to swallow. If swelling is severe it may become hard to breathe.

## Goals:

Call for professional help when needed.

- Prevent infection.
- Control pain.
- Maintain nutrition and fluid intake.

## Emergency signs and symptoms:

Call 911 **immediately** if:

- Not breathing.
- Severe difficulty breathing.

## Urgent signs and symptoms:

Call the clinic or after-hours clinic **now** if your child:

- Having difficulty breathing.
- Bright red in the mouth.
- Pain not controlled by medication.
- White patches or sores appear on gums or mouth.
- Difficulty swallowing food or fluid.

## Important signs and symptoms:

Report symptoms to a doctor or nurse during clinic hours today.

- White patches or sores appear on gums or mouth.
- Start to have difficulty eating or drinking.
- Increased sensitivity to foods or significant dryness.

## **What you and your child can do at home:**

### **Prevent infection and irritation:**

- Rinse mouth often with salt-water solution every 1 to 2 hours. Rinsing with solutions may also help reduce thickened secretions and should be done before eating, drinking, or taking medications by mouth.  
Recipe: 1 quart water,  $\frac{1}{2}$  to  $\frac{3}{4}$  level teaspoon salt. If the salt solution causes stinging or burning this may be relieved by diluting it or adding 1 to 2 teaspoons of baking soda.
- Spit secretions out often and especially before eating, drinking, or taking medications by mouth.
- Brush teeth twice a day with a very soft bristle toothbrush as long as your child is able. If it becomes too painful or significant bleeding occurs, a child's toothbrush or toothettes (sponge brushes) can be substituted. Resume using your normal toothbrush as soon as possible as it is more effective at keeping the bacteria under control and causes less trauma.
- Continue to floss daily as long as it is comfortable and no significant bleeding occurs.
- Avoid using commercial mouthwashes. Many contain alcohol or peroxide, which can dry and irritate your child's gums and the tissue in his or her mouth.

### **Control pain:**

- Topical anesthetics such as lidocaine viscous gel can be used to help control pain. They can be used as a rinse or applied directly to localized areas of soreness. These are prescribed by the doctor. They are jelly-like liquids which numb the mouth. These gels can be used full strength or diluted 1:1 or 1:2 if they cause stinging or burning. Fill a small container such as a medicine cup with the solution. Have your child take a small amount (5 to 10 ml) and swish and hold the solution in the mouth for 15-30 seconds. Repeat this until your child has used the entire volume of the cup. Repeat as often as needed. Do not swallow the solution. For single or small areas, try applying the gel with a cotton tip applicator or gauze square once for 15 to 30 seconds then reapply in 30 to 60 second intervals for a total of 3 to 5 minutes. Use the gel at least 15 minutes before or after eating. When used right, the medicine may provide 30 to 45 minutes of pain relief.
- Take pain medication as instructed.
- Tell the doctor or nurse if pain medication does not seem to be controlling your child's pain.
- For chapped lips apply lanolin creams, Chapstick® or Blistex® and lip balms that contain lanolin.
- Place ice packs on painful areas such as cheeks, lips, or throat for 10 to 15 minutes every 2 hours.
- Avoid pretzels, chips, tomato juice, orange juice, or hot drinks.
- All oral rinses can be kept in the refrigerator or placed in an ice bath. This can be soothing, help to reduce swelling, or control bleeding.

### **Maintain nutrition and fluid intake:**

- Warm fluids - try: chicken noodle soup, chicken broth, and tea.
- Cool fluids - try: popsicles, slushies, sports drinks, and Kool-Aid®.

# Nausea and vomiting

## Just the facts

Many patients experience nausea and vomiting at some time during the treatment process. It is one of the side effects of the chemotherapy and radiation. Contrary to what most people think, nausea and vomiting have little to do with your stomach. They are actions controlled by certain centers in your child's brain and are involuntary. Willpower alone cannot stop nausea and vomiting.

A number of things can trigger nausea and vomiting:

- Chemotherapy agents.
- Radiation.
- Persistent pain.
- Poor kidney and liver function.
- Medications such as some narcotics.
- Infections of the gastrointestinal tract.
- Electrolyte disturbances.
- Graft-versus-host disease.

Thankfully, just as medicine has advanced against cancer, great progress has been made in preventing and treating nausea and vomiting. Some patients have little or no nausea and vomiting and keep eating during most of the treatment process. Anti-nausea (antiemetic) medications are often started before radiation and chemotherapy and then continued on a regular schedule. Even if your child does not feel nauseated, he should take the medicine. The fact that you have not vomited means that the medicine is working. Many antiemetics can make your child feel tired or sleepy. Some people will feel jittery and restless.

## Your goals

- Take anti-nausea medicines.
- Maintain nutrition and fluid intake.
- Call for professional help when needed.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **now** if:

- Having uncontrolled (constant) nausea and vomiting.
- Blood or "coffee ground" appearing material in the vomit.
- Medicine not kept down because of vomiting.
- Weakness or dizziness, along with nausea/vomiting.
- Severe stomach pain while vomiting.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today if:

- Nausea persists without control from anti-nausea medications.
- Projectile vomiting.

## **What you and your child can do at home**

Prevent nausea and vomiting or manage symptoms well:

- Make sure your child takes anti-nausea medicine as instructed before nausea starts.
- Before chemotherapy, lie down in a quiet place for 15 to 20 minutes and relax.
- Wear loose fitting clothes.
- Use distraction, relaxation, or deep-breathing techniques such as tapes, visualization, or hypnosis techniques. Have your child try breathing through his mouth.
- Keep his mouth clean. Rinse with water often.
- Rest in a chair after eating, keeping head elevated.

## **Take anti-nausea medications**

- Some anti-nausea medicines can cause drowsiness or sleepiness. Do not allow your child to drive a car or operate any dangerous equipment while he is taking them.
- Do not drink alcohol while taking anti-nausea medicines.
- Because anti-nausea medicines can make your child drowsy, it is advisable to stay with your child throughout this treatment period.

## **Maintain nutrition and fluid intake**

- Eat small meals during the day so your stomach is not too full.
- Eat and drink slowly so only small amounts enter your stomach at one time.
- Avoid eating and drinking one hour before and one hour after chemotherapy.
- Stay away from sweet, fatty, or fried foods.
- Drink cool, clear fruit juices.
- Eat dry foods like toast or crackers to help ease nausea.
- Avoid odors that bother you. If food smells make you sick, avoid being in the kitchen when food is being prepared.
- Avoid food served at extreme temperatures.
- Keep a wide choice of food available.

## **Call for professional help when needed**

- If you notice that the anti-nausea medicine does not seem to control your child's nausea, call your doctor or nurse. Additional medications may be used to better control your nausea.
- If the medicines seem to make your child nervous, jittery, or cause any unusual sensations, let your doctor or nurse know.
- Do not increase the amount of medicine without checking with the doctor, nurse, or pharmacist.
- Do not take any over-the-counter medicines without checking first with your doctor or nurse.

# Pain

## Just the facts

Your child may experience pain during the course of his illness. Most pain can easily be treated with pain medication and/or other treatments. Your oncologist and nurse will assist you to find the best possible way to control his pain. On occasion your doctor may ask a doctor who specializes in cancer pain management to manage your child's pain. Pain is an unpleasant sensation that only your child can feel. It is what your child says it is. A change or increase in pain does not necessarily indicate that your cancer has returned or is progressing. Pain may be caused by a number of things including cancer, treatment of the cancer, or a medical problem not related to the cancer diagnosis.

## Myths about narcotics and opioids

- Some people will think they will become addicted. Research has shown that this is not true. If your child uses her pain medication the way her doctor prescribes it, it is very rare for her to become addicted.
- Some patients do not want narcotics because they fear the side-effects. Nausea, vomiting, sleepiness, constipation, and itching are common side effects, but can easily be managed by changing your child's medication or adding other treatments.

## Patient rights and responsibilities

As a patient of the SCCA, you and your child have the right to:

- Information about pain and pain management.
- Have your child's pain treated promptly.
- Have doctors and nurses who believe your child's report of pain.

## As healthcare providers, we expect you to

- Describe and rate your child's pain.
- Ask about pain management.
- Discuss options with your child's doctor or nurse.
- Ask for pain relief when your child first experiences pain.
- Inform us if pain treatment is not working.
- Help us develop a treatment plan for your child.

## Goals

- Report your child's pain.
- Rate your child's pain. Keep track of what triggers it and what makes it better.
- Have pain treated promptly.
- Maintain optimal level of physical activity.

## Assessment of pain

Your child's doctor or nurse will ask you or your child to "rate" her pain using a simple method. Remember, only your child knows what and where her pain is, and we need her to help us so that we can help her.

Your child's doctor or nurse will ask her to "point" to the area of her pain. They will also ask the following questions:

- What will cause the pain?

- What do you think will get rid of the pain?
- What is the quality of your pain? (burning, radiating, throbbing, stabbing)

It is the staff's goal to provide your child with the best possible treatment of her pain. We ask that you help us do so by telling us about your child's pain when she first experiences it.

### **How can we treat your child's pain?**

Your child's pain can be treated/managed in many different ways. Your child's doctor may choose to prescribe Tylenol®, ibuprofen, or narcotics/opioids such as morphine. Sometimes he/she may choose to use a local anesthetic. The method depends on the location and severity of your child's pain.

### **Non-drug methods of pain relief**

- Hot or cold packs.
- Massage/therapeutic touch.
- Hypnosis.
- Relaxation and music therapy.

### **Pain medication may be given different ways**

- Pills.
- Patch (like a bandage placed on the skin).
- Intravenous.
- SQ (under the skin).
- PCA-intravenous (a small computerized pump that lets you control how much pain medication you receive).
- Epidural (a small tube inserted into your back).

Some pain medications should be taken on a regular basis (long-acting medication), while others should be taken only when you begin to feel the pain (break-through medicine).

### **Emergency signs and symptoms**

Call 911 **immediately** if your child has:

- Severe chest/arm pain.
- Severe squeezing or pressure in chest.
- Severe sudden headache.

### **Urgent signs and symptoms**

Call the clinic or the after-hours clinic **now** if your child has:

- New or uncontrolled pain.
- New headache.
- Chest discomfort or heart "flip-flop" feeling.
- Pounding heart.
- Painful central line site or area of "tunnel".
- Burning in chest or stomach.
- Strong stomach pain.
- Pain with infusion of medications or fluids into central line.

## **What you and your child can do at home**

- Maintain your child's treatment plan and take medications as ordered. Do not increase your child's dose of medication without talking to your nurse or doctor.
- Keep a pain journal.
- Use hot or cold packs.
- Find a relaxation technique that works for your child such as meditation, guided imagery, hypnosis, massage, or therapeutic touch.
- Listen to relaxing music.
- Taking care of your child's pain will help her sleep better, feel stronger, and be better able to cope with her illness.
- Continue activities that are meaningful to your child. These activities may help your child notice less pain or discomfort.
- Before taking pain medication or opioids, ask your nurse or doctor about ways to prevent constipation.

# Peripheral neuropathy

## Just the facts

Peripheral neuropathy is damage to nerves that can span from your child's fingers to his toes. Peripheral means nerves beyond the brain and spinal cord. Peripheral nerves take information to the muscles, organs, skin, and joints, and then take information back to the brain. "Neuro" means nerves. "Pathy" means abnormal. When this occurs it can cause pain and numbness, or a sensation that is similar to burning or tingling. In many cases symptoms improve with time. There are many different causes. Some chemotherapy medications can cause this problem. Other causes include: traumatic injury, diabetes, infectious conditions, and toxic compounds.

## Goals

- Monitor onset of symptoms.
- Protect your hands and feet.
- Get professional help when needed.

## Emergency signs and symptoms

Call 911 **immediately** if:

- You cannot wake your patient.

## Urgent signs and symptoms

Call the clinic or the after-hours clinic **now** if:

- Your child is unable to move his legs.
- Your child has fallen.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Change in sensation symptoms: numbness, tingling, tremor, burning, loss of sensation, gait imbalance (unstable walking), sensitivity to touch, weakness, tiredness and heaviness.
- Movement symptoms: lack of muscle control, falling, muscle twitching, cramping, foot drop, and muscle atrophy.
- Autonomic symptoms: failure of the nerves to work correctly can result in abnormal blood pressure and digestive problems such as nausea, blurred vision, and dizziness.

## What you and your child can do at home

- You can meet with a physical therapist if your child is having problems with balance. Ask your team to schedule your child for a physical therapy appointment. Home equipment and/or devices to help your child walk independently may be recommended if he has mobility problems. Discuss with your doctor, nurse, and physical therapist safety measures you should put in place.
- Avoid extreme temperatures. Peripheral neuropathy may make areas of your body more sensitive to hot or cold.
- Have your child wear shoes, slippers, gloves, and other clothing to protect his skin from changes.
- Use extra care when using hot, sharp, or potentially harmful objects. Your child may be more at risk for clumsiness and prone to injury if he has reduced sensations.
- Avoid falls - review the Fall Prevention symptom sheet in this manual. If your child has sensation changes, you are more at risk for falls.

- Check your child's feet every day, looking carefully at the bottom of his feet and toes for any changes.

For lack of sensation in your child's hands:

- Check temperatures with inner forearms to avoid burns.
- Always use protective padding for cooking and rubber gloves for cleaning.
- Keep finger nails short to avoid tearing.
- Keep hands moisturized to avoid skin breaks from dryness.

### **Coping with peripheral neuropathy**

- Your child's doctor will try to determine the source of the problem. Ask your doctor questions.
- Let your child's care team know how much the neuropathy impacts his life. There are techniques for coping with pain and discomfort. In many cases, symptoms improve with time.

### **Websites**

[www.neuropathy.org](http://www.neuropathy.org)

# Sexual health

## Just the facts

Treatments such as chemotherapy, surgery and radiation may cause changes that can affect intimacy and sexuality, including desire and body image. We want to be sure young adults experiencing cancer treatment are prepared for the physical and emotional changes that they may experience during this time. We encourage them to:

## Goals

- Discuss any restrictions and questions with their care team.
- Keep an open mind about the possibility of needing to adjust to physical and emotional sexual changes that occur; communicate openly with partner(s).
- Have a pleasurable experience (free from pain or risk).
- Prevent infection.

If young adults are sexually active, it is important to **prevent infection, pregnancy, or fathering a child.**

### PREGNANCY AND CHEMOTHERAPY

**Chemotherapy can have harmful effects on pregnancy. If there is a chance young adults who are sexually active during treatment could become pregnant or father a child while undergoing chemotherapy or radiation, talk to the care team about birth control.**

## Young adults who are sexually active should talk to their care team if they experience

- Pain, discomfort, or bleeding during or after sex.
- Fear about sexual activity.
- Lack of desire that is affecting their relationships.
- **Young women:** vaginal dryness, discharge, pelvic pain, or menopausal symptoms such as hot flashes or loss of menstrual cycle
- **Young men:** pain during penetration or ejaculation, abnormal discharge, changes in his ability to get erections or ejaculate

## What can be done at home

### Young adults who are sexually active should optimize positive feelings of intimacy:

- Plan sexual activity for the time of day when they are feeling best. If young adults are taking pain medication, they can take it at an hour when it will be in full effect during sex.
- Talk about expectations and what might feel good, or what to avoid.
- Consider other forms of intimacy—holding hands, snuggling, kissing, self-stimulation, and talking can happen at any stage of cancer treatment.
- Find a position or activity that puts as little pressure as possible on the sensitive or painful areas of the body.
- Empty the bladder before sexual activity.
- Communicate with partners to let them know if any kinds of touching causes irritation or pain.
- Use a sexual lubricant to help dry skin areas be slippery.

### **Prevent infection:**

- Wash hands before and after sexual activity.
- Urinate after sex. This rinses out bacteria that may cause infection in the urinary tract.
- Avoid sexual contact with people who have infectious diseases (colds, flu, cold sores) or sexually transmitted infections.

## **Common questions about sex during chemotherapy**

### **Is it safe for me to kiss while I'm receiving chemotherapy or after treatment?**

To reduce the risk of infection, avoid kissing anyone who has open mouth sores, cold sores, a cold, the flu, or symptoms of a respiratory infection.

### **What are restrictions for sexual activity?**

- When platelet counts are less than 50,000. This is due to the risk for bleeding.
- When white blood counts are low. Neutrophil (ANC) count should be more than 500 to prevent infection with most sexual activity. An ANC of 1,000 or more is needed for anal sex.
- Vaginal or rectal bleeding, sores in your mouth, vagina or rectum.
- If your partner has infections or open sores. Condoms are not always effective at preventing infections.

### **Why don't I have much sexual desire?**

- Lack of desire (also called lack of libido) and fatigue can be a normal response to the stresses of treatment, some medications, and changes in hormone levels.
- Young adults who are sexually active can talk to their partner or a counselor, and sometimes hormone replacement can be helpful. Talk to the care team so they can help find something that works.

### **Will I be infertile after treatment?**

- Factors that influence fertility include: type and dose of chemotherapy, radiation, and other medications; if young adults have had a transplant; and age at time of treatment.
- Young women often stop having periods but resume their menstrual cycle after treatment; some young women resume normal menstrual cycles but are still unable to become pregnant due to damage to eggs in the ovary; still, other young women may experience complete menopause.
- Young men often stop making sperm completely or have very low sperm counts during and for several months after cancer treatment. Not every male will resume normal sperm production and may be infertile.
- Testing of sex hormones, sperm counts, or ovarian function is needed to see if fertility is intact.
- If young adult patients are interested in preserving fertility, talk with the care team **before** treatment. This gives young men and women the opportunity to store sperm, eggs, or embryos when appropriate.
- A fertility specialist (reproductive endocrinologist) can provide more information about fertility status and the options available before and after treatment.
- Fertility services are not always covered by insurance, but financial assistance may be available. Don't let fear of cost prevent you from asking what services are possible.

### **What options do I have to store my eggs or sperm?**

- **For young men**, sperm banking is the standard approach. Sperm can be collected several different ways, but the simplest is to provide a sample of ejaculated semen. Sperm can be safely frozen for many years.

- **For young women**, the standard approach is to collect eggs, which can require hormone therapy and a medical procedure. This process can take up to 2 weeks. Eggs can be frozen individually or fertilized with sperm to create embryos before freezing. Eggs and embryos can be safely frozen for many years.

## Brochures and books

SCCA's Patient and Family Resource Center on the 3<sup>rd</sup> floor of the clinic offers brochures and books that young adults check-out. Some titles we suggest include:

- Katz, Anne. **Man Cancer Sex**. First Edition. Pittsburgh, PA: Hygeia Media: An Imprint of the Oncology Nursing Society, 2010.
- Katz, Anne. **Woman Cancer Sex**. First Edition. Pittsburgh, PA: Hygeia Media: An Imprint of the Oncology Nursing Society, 2009.
- Katz, Anne. **This Should Not Be Happening: Young Adults with Cancer**. First Edition. Pittsburgh, Pennsylvania: Hygeia Media, an imprint of the Oncology Nursing Society, 2014
- Kydd, Sally and Rowett, Dana. **Intimacy After Cancer: A Woman's Guide**, First edition. Big Think Media, 2006.
- Ellsworth, Pamela. **One Hundred Questions & Answers about Erectile Dysfunction**, Second edition. Sudbury, MA: Jones and Bartlett Publishers, 2008.

## Websites

Please visit <https://www.seattlecca.org/emotional-and-spiritual-support/medical-support-services/sexuality-resources> for a list of resources. You can also visit the following websites:

### American Cancer Society

[www.cancer.org](http://www.cancer.org)  
[www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/how-cancer-affects-sexuality.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/how-cancer-affects-sexuality.html)

### LIVESTRONG

[www.livestrong.com/sscat/sexual-health/](http://www.livestrong.com/sscat/sexual-health/)  
[www.livestrong.org/we-can-help/livestrong-fertility](http://www.livestrong.org/we-can-help/livestrong-fertility)

### Look Good Feel Better

[www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org)

### Save My Fertility & The Oncofertility Consortium

[savemyfertility.com](http://savemyfertility.com)  
[www.oncofertility.northwestern.edu/](http://www.oncofertility.northwestern.edu/)  
 Fertility resources before and after treatment

### University of Washington Reproductive Care

(206) 598-4225  
[www.uwmedicine.org/locations/reproductive-care-uwmc-roosevelt](http://www.uwmedicine.org/locations/reproductive-care-uwmc-roosevelt)

### University of Washington Sperm Cryopreservation Program

(877) 520-5000  
[www.uwmedicine.org/locations/mens-health-center/male-fertility-lab-\(mfl\)](http://www.uwmedicine.org/locations/mens-health-center/male-fertility-lab-(mfl))

## Products

SCCA's oncology store, Shine, has trained staff to help you identify which products are most appropriate for you. Feel free to call (206) 606-7560 for an appointment and consultation or visit the website at [www.sccashine.org](http://www.sccashine.org).

# Sleep problems

## Just the facts

People undergoing cancer treatment may experience changes in normal sleep patterns for a number of reasons, including: response to medications, discomfort, alteration in normal activity patterns, hospital stays, and emotional distress. Problems with sleep are associated with fatigue. Up to 50% of patients with cancer have sleep problems.

## Goals

- Prevent insomnia.
- Call for professional help when needed.

## Emergency signs and symptoms

Call 911 **immediately** if your child is unconscious.

## Urgent signs and symptoms

Call the clinic or the after-hours number **now** if your child:

- Has not slept in days.

## What you and your child can do at home

Promote sleep:

- Keep a regular schedule.
- Create a bedtime routine. Use a preferred relaxation technique such as reading, or taking a warm bath or shower.
- Back rubs or massages may be relaxing.
- Avoid alcohol, caffeine, and nicotine before bed.
- Maintain a healthy diet.
- Decrease negative associations with bed time. Do not stay in bed when not sleeping. Do not lie in bed while worrying.
- Do not exercise right before bedtime.
- Avoid electronic devices before sleep such as cell phone, television, and computer.
- Use the bed for sleep and sex only.
- Create a peaceful environment in which to sleep by decreasing noise, dimming lights, adjusting room temperature, and keeping bedding and pillows clean, dry, and wrinkle-free.
- Try not to drink fluid before bed and empty bowel and bladder before bedtime.
- Minimize daytime naps.
- Listen to relaxation tapes and or peaceful music before bed.

## Call for professional help when needed

- If your child is not sleeping.

# White blood cells

## Just the facts

A white blood cell count with differential provides information about your white blood cells. White blood cells help protect the body by fighting bacteria and viruses that cause infection. It is important to protect yourself against infection. When your child's white blood count is low, they are more prone to infection.

## Goals

- Recognize signs of infection.
- Get professional help when needed.

## Important signs and symptoms

Report symptoms to a doctor or nurse during clinic hours today.

- Shaking or chills.
- Cough.
- Temperature greater than or equal to 38.3°C (100.9°F), or a temperature of 38.0°C (100.4°F) for 1 hour.
- When taking an axillary (under the arm) temperature with children, call if the temperature is 37.9°C (100.3°F) or higher.
- Sore throat.
- A general feeling of tiredness or "flu-like" symptoms.
- Painful or frequent urination.

## What you and your child can do at home

Preventive measures:

- Look at your mouth and skin for signs of infection. Exercise excellent mouth care. See Mucositis information sheet.
- Have your child brush her teeth after each meal and at bedtime. Use a soft-bristle toothbrush and be careful to avoid injury to the gums. Avoid use of mouthwashes that contain alcohol.
- Keep your child's skin clean and avoid cuts and scratches. Report any changes in skin including rashes, sores, and cuts.
- Wash hands frequently.
- Wear gloves when washing dishes.
- Shave with an electric razor.
- Use lotion for dry skin.
- If your child has hemorrhoids, ask her doctor or nurse for advice before self-treatment.
- Check with your doctor or nurse regarding dental work.

# Food safety guidelines

## Overview

Foodborne illness, or “food poisoning,” is any illness caused by eating a food that is contaminated with a bacteria, virus, mold or parasite. Examples of organisms that can cause a food borne illness are *E. coli*, *Salmonella* and *Listeria*. Sources of foodborne illness may be the food handler, the environment (such as a contaminated work surface) or the food itself.

Bacteria and other organisms exist commonly in foods. Most of these organisms are of little risk to the average healthy person. However, persons undergoing chemotherapy, radiation, or a hematopoietic cell transplant are at increased risk for infections, including foodborne illness. By following safe food practices, patients and caregivers can reduce the risk of foodborne illness.

All hematopoietic cell transplant patients are recommended to follow the “*Immunosuppressed Patient Diet*”. In addition, it is recommended that all patients follow the food safety guidelines discussed below. If you have any questions regarding food safety and diet guidelines, talk to your dietitian.

## Steps to food safety

- Wash hands and surfaces often
- Avoid cross-contamination of foods
- Keep foods at safe temperatures

## Tools for food safety

- Food and refrigerator thermometers
- Hand soap
- Clean towels (cloth or paper)
- Bleach solution (for washing countertops, cutting boards and other items)

**\*Dilute bleach solution:** Mix 1/3 cup unscented household bleach with 3 1/3 cups water. (This will make a total of 3 2/3 cups of bleach solution.) This solution must be remade daily.

## Hand hygiene

- Wash hands frequently with soap and warm, running water and rubbing motion (friction) for 15 seconds before and after every step in food preparation. This is critical before and after handling raw meat, seafood and poultry.
- Wash hands before eating and after using the rest room, handling garbage, and touching pets.
- Dry hands with a paper towel or cloth hand towel that is changed daily.

## Kitchen cleanliness

### Overview

- Replace dishcloths and dishtowels daily. They should be laundered in the hot cycle of your washing machine.
- Sanitize sponges daily and after contact with raw meat, fish and eggs. You may soak them in the dilute bleach solution\* for five minutes, heat them in a microwave oven on high for one minute, or run them through the dishwasher.
- Use liquid dish soap and very warm water when hand-washing dishes, pans, and utensils. Air-dry dishes instead of towel-drying them.
- Wash counters, utensils, and can openers with soap and hot water immediately after use. After washing, they can be sanitized using the dilute bleach solution.\*
- Keep the refrigerator clean. Clean spills immediately. Wash shelves and doors weekly using the dilute bleach solution.\*
- Make sure food storage areas remain clean.
- Rotate food stock so older items are used first. Check expiration dates. Do not use foods past the expiration dates.
- Throw away any bulging, leaking or cracked cans, or those deeply dented in the seam area. Do *not* taste these foods.
- Keep appliances free of food particles (including the microwave oven, toaster, can opener, blender and mixer blades). Blender blades and the bottom ring should be removed from the blender after each use and washed in hot, soapy water.
- Keep food storage areas clean. Do not store any food supplies under the sink. Do not store chemicals and cleaning solutions over or near food supplies.

### Cutting boards

- Wash cutting boards with hot, soapy water after each use; then rinse and air-dry or pat dry with fresh paper towels. Non-porous acrylic, plastic or glass boards and solid wood boards can be washed in a dishwasher (laminated boards may crack or split).
- Sanitize both wooden and plastic cutting boards with the dilute bleach solution.\* This should be done every time the board is used for raw meat, fish and poultry. Sanitize cutting boards used for other purposes at least once weekly. Flood the surface with the bleach solution and allow it to stand for at least 2 minutes, then rinse and air-dry or pat dry with fresh paper towels. Alternatively, use a commercial sanitizing agent (that contains bleach) and follow the directions on the product.
- Replace worn cutting boards, including boards with cracks or grooves.

## Safe food handling: from the grocery store to your home

### Grocery store

- Shop for shelf-stable items first (shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the container may require refrigeration after opening.)
- Select frozen and refrigerated foods last, especially during the summer months.
- Check “Sell By” and “Use By” dates on dairy products, eggs, cereals, canned foods, and other goods. Select only the freshest products.
- Check packaging dates and “use by” dates on fresh meats, poultry, and seafood. Do not purchase if they are outdated.
- Do not use damaged, swollen, rusted, or deeply dented cans. Check that packaged and boxed foods are properly sealed.
- Select fruits and vegetables that are not moldy, bruised or damaged. Fresh fruits and vegetables should look fresh. Wilted salad greens may be an indication that the product is old and not properly handled.
- Avoid unpasteurized juice (unless prepared at home with washed produce).
- Choose shelf-stable salsa rather than salsas found in the refrigerator section of the grocery store.
- Avoid unpasteurized milk, yogurt, cheese, other unpasteurized milk products, including Mexican-style cheese made from unpasteurized milk (such as queso fresco).
- Do not use foods with any mold present, including blue cheese.
- Avoid unrefrigerated, cream- and custard-filled pastry products, such as fresh bakery cream pies, Éclairs, cream-filled donuts and pastries. Commercial, shelf-stable items such as Danish pastries are allowed. Follow the “use by” date and store them according to the manufacturer’s guidelines after opening.
- Avoid foods from “reach in” or “scoop” bulk food containers. Avoid food from any type of bulk food container if it will not be cooked prior to consumption.
- Do not taste unpackaged food samples.
- Choose eggs that are refrigerated in the store. Do not use cracked eggs. Pasteurized eggs, liquid pasteurized egg products (such as EggBeaters®) and powdered egg whites may be used in recipes calling for raw eggs in foods that will not be cooked.
- Place meat, poultry and fish in plastic bags. Ask to have these items placed in separate bags from the fresh produce and ready-to-eat foods when at the checkout stand.
- Never leave perishable food in the car. Refrigerate or freeze them promptly.

### Home

- Wash the tops of canned foods before opening. Clean the can opener after each use.
- Throw away eggs with cracked shells.
- Throw away foods older than their “use by” expiration dates.
- Throw away entire food packages or containers with *any* mold present, including yogurt, cheese, cottage cheese, fruits (especially berries), vegetables, jelly, bread, cereal and pastry products.

### Fruit and vegetable handling

All fresh produce (whether organic, natural or general produce) may carry dangerous bacteria or other organisms that can cause food borne illness. Bacterial contamination can occur in the fields from the use of natural fertilizers (such as animal manure) or from human contact during produce harvesting, transporting and in the grocery store.

**The term “organic” or “natural” refers to growing without the use of chemical fertilizers or pesticides and has no relationship to the cleanliness or safety of the produce.**

Use the following guidelines for handling *all* raw produce, including organic, organically grown, “**natural**” and general produce:

- Refrigerate fruits and vegetables promptly.
- Do not purchase produce that has been cut at the grocery store (such as melon or cabbage halves). This is particularly true for produce that will not be cooked prior to eating.
- Rinse produce thoroughly under **clean, running water** just before use, including produce that is to be peeled (such as bananas, melons and oranges) or cooked. Do not wash fruits and vegetables with soaps, detergents or chlorine bleach solutions. Produce can absorb these cleaning agents.
- Commercial produce rinses (such as Fit® Fruit and Vegetable Spray) are not recommended since they have not been shown to be more effective for removing bacteria off the produce than washing under running water.
- Scrub produce that has a thick, rough skin or rind (such as cantaloupe or potatoes) or has visible dirt on the surface using a clean vegetable scrubber.
- Rinse leaves of leafy vegetables (such as lettuce, spinach, cabbage) individually under running water.
- Packaged salads, slaw mixes and other prepared produce, even when marked pre-washed, should be rinsed again under running water; a salad spinner or colander can be used to make this easier. Check for “**use by**” dates.
- Do not eat any raw vegetable sprouts (avoid **all** types, including alfalfa sprouts, clover sprouts, mung bean sprouts, and so on) due to high risk of Salmonella and *E. coli* contamination. Cooked mung bean sprouts are acceptable.
- Throw away fruits and vegetables that are slimy or show mold.
- Review the processing procedure if preparing home-canned foods. Be sure the procedure is appropriate for the acidity of the food, size of the bottle, and elevation above sea level. Look for mold and leaks. Check seals. *If you suspect a home-canned food may not have been properly processed (for example, if the lid bulges or if the food has any bad odor or unusual characteristics after opening), THROW IT AWAY. It is recommended to use home canned foods within one year of canning as chemical changes may occur.*

#### **Avoid cross contamination**

- Use a clean knife for cutting different foods (for example, use different knives for cutting meat, produce and bread).
- During food preparation, do not taste the food with the same utensil used for stirring. Use a clean utensil each time you taste food while preparing or cooking.
- In the refrigerator, store raw meat separately from ready-to-eat foods.
- When grilling, always use a clean plate and utensils for the cooked meat.

## Keep foods at safe temperatures

### Proper thermometer use

- Test a thermometer's accuracy by putting it into boiling water. It should read 212°F.
- Read the manufacturer's instructions. Insert the meat thermometer into the middle of the thickest part of the food to test for doneness. The entire part of the stem, from the dimple to the tip, must be inserted into the food. For thin foods, insert the thermometer sideways.
- A refrigerator thermometer should be placed on a shelf toward the back of the refrigerator. It should read 40°F or less.

### Refrigeration

- Keep the refrigerator temperature between 34°F to 40°F.
- Keep the freezer temperature below 0°F to 2°F.
- Never leave perishable food out of the refrigerator for over **two hours**. Throw away food left out longer than two hours.
- Marinate foods in the refrigerator.
- Thaw foods in the refrigerator, never on the counter.
- Thaw meat, fish or poultry in the refrigerator away from raw fruits and vegetables and other prepared foods. Place on a dish to catch drips. Cook defrosted meat right away; do not refreeze. If you are in a hurry you can thaw meat in the microwave. **The meat must be cooked immediately after thawing.**
- Cool hot foods uncovered in shallow containers in the refrigerator. Cover storage containers after cooling. Make sure that covers seal tightly.
- Throw away all prepared food after 72 hours (3 days). Use labels or masking tape to write dates on containers.
- Freeze foods that will not be used within 2 to 3 days.
- NEVER TASTE FOOD THAT LOOKS OR SMELLS STRANGE!

### Cook foods adequately

- Cook meat until it is no longer pink and the juices run clear. These are signs that the meat may be cooked to a high enough temperature. However, the only way to be sure that the meat has been cooked to the proper temperature is to use a food thermometer (See Table 1 on the next page).
- Thoroughly heat until steaming (165°F) all hot dogs and "ready to eat" luncheon meats, cold cuts and "deli-style" meats before eating.
- Do not eat raw, lightly cooked, or soft boiled eggs.
- Do not eat uncooked foods containing raw or undercooked eggs, such as raw cookie dough, cake batter or salad dressings containing raw or coddled eggs.
- Pasteurized eggs and liquid pasteurized egg products (such as EggBeaters®) may be used in recipes calling for raw eggs in foods that will not be cooked.
- Hold food at safe temperatures: hot food **above** 140°F, cold food **below** 40°F.

## Recommended minimum cooking temperatures

| Product                                                             | Cooking temperature or visual characteristics                                                      |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------------------|
| Eggs, egg dishes, and casseroles                                    |                                                                                                    |
| Eggs                                                                | Cook until yolk and white are firm                                                                 |
| casseroles, foods containing eggs, custards and egg sauces          | 160°F                                                                                              |
| Veal, beef, pork, lamb, rabbit, goat, game                          |                                                                                                    |
| Whole pieces meat                                                   | 160°F                                                                                              |
| Ground veal, beef, lamb, pork, rabbit, goat, game                   | 160°F                                                                                              |
| Poultry (chicken, turkey, duck, goose)                              |                                                                                                    |
| Chicken and turkey: whole bird and dark meat (leg, thigh, wing)     | 180°F                                                                                              |
| Breast, roast                                                       | 170°F                                                                                              |
| Ground chicken, turkey                                              | 165°F                                                                                              |
| Stuffing (always cook in separate container outside of bird)        | 165°F                                                                                              |
| Ham                                                                 |                                                                                                    |
| Fresh (raw)                                                         | 160°F                                                                                              |
| Pre-cooked (to reheat)                                              | 160°F                                                                                              |
| Seafood                                                             |                                                                                                    |
| Fin fish (such as salmon, cod, halibut, snapper, sole, bass, trout) | Cook until opaque and flakes easily with a fork                                                    |
| Shrimp, lobster, crayfish, crab                                     | Should turn red and flesh should become pearly opaque                                              |
| Scallops                                                            | Should turn milk white or opaque and firm                                                          |
| Clams, mussels, oysters                                             | Cook until shells open (may be high risk food for people with low white count or immunosuppressed) |
| Leftovers, hot dogs, and luncheon meats                             |                                                                                                    |
| Leftovers                                                           | 165°F                                                                                              |
| Hot dogs, luncheon meat                                             | Steaming hot                                                                                       |

### Microwave cooking

- Microwave cooking can leave cold spots in food where bacteria can survive. Rotate the dish a quarter turn once or twice during cooking if there is no turntable in the appliance.
- When heating leftovers, use a lid or vented plastic wrap to cover them. Stir several times during reheating. When the food is heated thoroughly (to a minimum of 165°F), cover and let sit for 2 minutes before serving.

## **Additional guidelines for general oncology patients with low white blood count\* and all stem hematopoietic transplant patients**

\*Low white blood cell count refers to a neutrophil count less than 1000mm<sup>3</sup> or when chemotherapy is held due to low neutrophil count.

### **Dining out safely**

- Eat early to avoid crowds.
- Ask that food be prepared fresh in fast food establishments (for example, a hamburger should be fresh off the grill, not one that has been sitting under heat lamps).
- Ask if fruit juices are pasteurized.
- **Avoid raw fruits and vegetables when dining out.** Eat these items when prepared at home, where you can wash them thoroughly and prepare them safely.
- Ask for single-serving condiment packages. Do not use public self-serve condiment containers, including salsa.
- Avoid salad bars, delicatessens, buffets and smorgasbords, potlucks and sidewalk vendors.
- Be sure that utensils are set on a napkin or clean tablecloth or placement, rather than directly on the table.
- Check the general condition of the restaurant. Are the plates, glasses, and utensils clean? Are the restrooms clean and stocked with soap and paper towels? How clean the restaurant looks may tell the amount of care taken while preparing the food.
- If you want to keep your leftovers, ask the server to bring you a box into which you can transfer the food yourself, rather than having your food transferred into a box in the restaurant kitchen. Be sure to take home and refrigerate the leftovers immediately.

### **Other foods**

- Do not eat soft cheeses such as feta, Brie, Camembert, blue-veined, Stilton or Mexican-style cheese (queso fresco).
- Cut tofu into 1-inch cubes or smaller and boil 5 minutes in water or broth before eating or using in recipes. (Note: This process is not needed if using pasteurized tofu or aseptically packaged shelf-stable tofu such as Mori-Nu<sup>®</sup> silken tofu.)
- Choose shelf-stable salsas and salad dressing (shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored at room temperature before opening; the container may require refrigeration after opening.) Avoid fresh fruit or vegetable salsas and salad dressing found in the refrigerated section of the grocery store.
- Do not consume raw honey or honeycomb. Choose **Grade A** honey.

# Water safety guidelines

## Overview

Public water quality and treatment varies throughout the United States, so always check with the local health department and water utility regarding the safety of household and community tap water and ice for use by immunosuppressed persons.

## Tap water

Water from your home faucet is considered safe if your water is from a city water supply or a municipal well serving highly populated areas.

## Well water

Well water from private or small community wells is not considered safe for consumption by persons considered immunosuppressed and at risk for infection unless it is tested daily and found to be negative for coliforms and *Cryptosporidium* organisms.

### Examples of ways well water could become contaminated:

- construction occurs near the well
- well depth is shallow
- well is located near a dairy farm or large numbers of livestock
- flooding has recently occurred in the well area

**Municipal wells:** Drinking well water from municipal wells serving highly populated areas is considered safe because the water is tested for bacterial contamination more than two times each day.

**Private and small community wells:** The quality of well water from these sources cannot be guaranteed unless it is tested daily and found to be negative for coliforms and *Cryptosporidium* organisms. It is recommended that other approved water sources be used instead, including: boiled water or bottled water (see guidelines below).

**Not considered safe:** Common home water filtration devices *do not* remove bacteria or viruses. If the well water supply is chlorinated per guidelines provided by your local health department, the chlorinated water treated with one or more of the following is considered safe to consume:

- Reverse osmosis treated
- Distillation
- Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)
- See “Water Filters” (below).

## Safe water sources

The following sources of water are suggested if your water is not from a city water or municipal well supply:

### • Boiled Water

At home, safe water can be made by bringing tap water to a rolling boil for one minute. After processing, the water should be stored in a clean, covered container in the refrigerator; discard water not used within 72 hours (3 days).

### • Distilled Water

Water may be distilled using a steam distillation system. After processing, the water should be stored in a clean, covered container in the refrigerator; discard water not used within 72 hours (3 days).

### • Bottled Water

Acceptable forms of bottled water have been processed to remove organisms known to cause stomach or

intestinal infection. Bottled water labels reading “well water”, “artesian well water”, “spring water”, or “mineral water” *do not guarantee* that the water is safe to drink. Water labeled as having been treated with one or more of the following are considered safe:

- Reverse osmosis treated
- Distillation
- Filtered through an absolute 1 micron or smaller filter (NSF Standard #53 for cyst removal)

To be sure that a specific brand of bottled water has undergone one of the above processes, contact the International Bottled Water Association (IBWA) at 1-800-928-3711, or visit their home page at [www.bottledwater.org](http://www.bottledwater.org). If the IBWA does not have information on a specific brand, call the bottling company directly.

IBWA follow more strict manufacturing practices in their water bottling process than those practices currently mandated by the United States Food and Drug Administration. Therefore, water bottled by a member of the IBWA may be preferable to water produced by non-member bottlers.

## Water filters

*Most water filtration devices will not make the water safe if the water supply has not been previously chlorinated.* If you choose to install water filters on household water taps purchase only filters certified by NSF International. The following specifications must also be met:

- a. The filters must be designed to remove coliforms and *Cryptosporidium*. Any of the following are acceptable:
  - Reverse osmosis filter
  - Absolute pore size of filter 1 micron or smaller
  - Tested and certified by NSF Standard #53 for cyst removal
- b. The water tap filter must be installed immediately before the water tap
- c. Manufacturer directions must be followed for filter maintenance and replacement

Portable water filters (such as a Brita® or Pur® system) as well as refrigerator-dispensed water and ice machine systems do not meet filtration standards. Portable water systems filter out chemical impurities, not bacteria. If a portable water system (such as a Brita® pitcher) is used in combination with a safe water supply (to improve water flavor and remove chlorine and other impurities), it is recommended to change the system’s filters frequently according to manufacturer’s guidelines.

For a list of approved filtration systems, call the *National Sanitation Foundation International*, at 1-800-673-8010 or visit their home page at [www.NSF.org](http://www.NSF.org) (go to the section entitled “Home Water Treatment Devices”).

# Diet guidelines for immunosuppressed patients

## Overview

You may have decreased immune function because of chemotherapy and/or radiation therapy or from taking medications to suppress your immune system. This means that you are at increased risk of developing a food-related infection. The purpose of this diet is to help you avoid specific foods that are more likely to contain infection-causing organisms while allowing maximum healthy food choices. Choose foods from the “May Eat” column. Do not eat foods in the “Do Not Eat” column. You may want to discuss the safety of these or other foods with your dietitian.

This diet should be followed before and after all conditioning therapy (chemotherapy and/or radiation) and while on immunosuppressive medications. Your health care provider and dietitian will let you know when the diet is no longer required. In general, we recommend the following:

- **For autologous transplant patients undergoing chemotherapy treatment only:** Follow this diet during the first three months after chemotherapy or transplant.
- **For allogeneic transplant patients:** Follow the diet until you are off all immunosuppressive therapy such as cyclosporine, prednisone, Tacrolimus®, Myfortic®, sirolimus, or MMF.

Before end of these time periods, you and your caregiver should talk to your health care provider and dietitian regarding whether or not to continue any part of the diet.

| Food groups                                                                                      | May eat                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Do not eat                                                                                                                                                                                                                                                                                                                         |
|--------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Dairy</b>  | <ul style="list-style-type: none"> <li>• All pasteurized, grade “A” milk and milk products including eggnog, yogurt, ice cream, frozen yogurt, sherbet, ice cream bars, milkshakes, processed cheese slices and spreads, cream cheese, cottage cheese and ricotta cheese</li> <li>• Dry, refrigerated, or frozen pasteurized whipped topping</li> <li>• Commercially packaged hard and semi-soft cheeses such as cheddar, mozzarella, parmesan, Swiss, Monterey Jack, etc.</li> <li>• Cooked and pasteurized soft cheeses such as brie, goat, camembert, feta, farmer’s cheese. Though not completely risk free, the risk of contracting food borne illness from COOKED soft cheeses is low</li> <li>• Mexican-style soft cheese such as queso fresco, queso blanco (unless made with pasteurized milk and cooked)</li> <li>• Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available)</li> </ul> | <ul style="list-style-type: none"> <li>• Non-pasteurized or raw milk and milk products made from non-pasteurized or raw milk</li> <li>• Cheeses from delicatessens</li> <li>• Cheese containing chili peppers or other uncooked vegetables</li> <li>• Cheeses with molds (such as blue, Stilton, Roquefort, gorgonzola)</li> </ul> |

| Food groups                                                                                                               | May eat                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Do not eat                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|---------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p><b>Meat and meat substitutes</b></p>  | <ul style="list-style-type: none"> <li>• All meats cooked to well done (see temperature guide attached) or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs)</li> <li>• Eggs cooked until both white and yolk are firm</li> <li>• Pasteurized eggs and egg substitutes (such as Egg Beaters®), and powdered egg white (all can be used uncooked)</li> <li>• Commercially-packaged salami, bologna, hot dogs, ham and other luncheon meats, heated until steaming</li> <li>• Canned and shelf-stable<sup>1</sup> smoked fish (refrigerate after opening)</li> <li>• Pasteurized or cooked tofu<sup>2</sup></li> <li>• Refrigerated smoked seafood such as salmon or trout if cooked to 160°F or contained in a cooked dish or casserole</li> </ul> | <ul style="list-style-type: none"> <li>• Raw or undercooked meat, poultry, fish, game, tofu<sup>2</sup></li> <li>• Raw or undercooked eggs and non-pasteurized egg substitutes; no eggs over easy, soft-boiled eggs, or poached eggs</li> <li>• Meats and cold cuts from delicatessens</li> <li>• Hard cured salami in natural wrap</li> <li>• Uncooked refrigerated smoked, seafood such as salmon or trout labeled as “nova-style,” “lox,” “kippered,” “smoked” or “jerky”</li> <li>• Pickled fish</li> <li>• Tempe (tempeh) products</li> </ul> |
| <p><b>Fruits and nuts</b></p>          | <ul style="list-style-type: none"> <li>• Well-washed<sup>3</sup> raw and frozen fruit; foods containing well washed raw fruits</li> <li>• Cooked, canned and frozen fruit</li> <li>• Pasteurized juices and frozen juice concentrates</li> <li>• Dried fruits</li> <li>• Canned or bottled roasted nuts</li> <li>• Shelled, roasted nuts and nuts in baked products</li> <li>• Commercially-packaged nut butters (such as peanut butter, almond butter, soybean butter)</li> </ul>                                                                                                                                                                                                                                                                                                             | <ul style="list-style-type: none"> <li>• Unwashed raw fruits</li> <li>• Unroasted raw nuts</li> <li>• Roasted nuts in the shell</li> <li>• Non-pasteurized fruit and vegetable juices</li> <li>• Fresh fruit salsa found in the grocery refrigerator case</li> <li>• Non-pasteurized items containing raw fruits found in the grocery refrigerator case</li> </ul>                                                                                                                                                                                 |

<sup>1</sup> Shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored before opening at room temperature; container may require refrigeration after opening.

<sup>2</sup> Aseptically packaged, shelf-stable tofu and pasteurized tofu do not need to be boiled. Unpasteurized tofu must be cut into 1-inch cubes or smaller and boiled a minimum of five minutes in water or broth before eating or using in recipes.

<sup>3</sup> Rinse under clean, running water before use, including produce that is to be cooked or peeled (such as bananas, oranges and melon).

| Food groups                                                                                                                     | May eat                                                                                                                                                                                                                                                                                                                                                                                                                          | Do not eat                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|---------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Entrees and soups</b><br>                   | <ul style="list-style-type: none"> <li>All cooked entrees and soups</li> </ul>                                                                                                                                                                                                                                                                                                                                                   | <ul style="list-style-type: none"> <li>All miso products (such as miso soup and miso paste)</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Vegetables</b><br>                          | <ul style="list-style-type: none"> <li>Well washed<sup>3</sup> raw and frozen vegetables</li> <li>All cooked fresh, frozen or canned vegetables, including potatoes</li> <li>Shelf-stable<sup>1</sup> bottled salsa (refrigerate after opening)</li> <li>Cooked vegetable sprouts (such as mung bean sprouts)</li> <li>Fresh, well washed<sup>3</sup> herbs and dried herbs and spices (added to raw or cooked foods)</li> </ul> | <ul style="list-style-type: none"> <li>Unwashed raw vegetables or herbs</li> <li>Fermented vegetables such as kimchi or sauerkraut</li> <li>Fresh, non-pasteurized vegetable salsa found in the grocery refrigerator case</li> <li>Non-pasteurized items containing raw vegetables found in the grocery refrigerator case</li> <li>All raw vegetable sprouts (alfalfa sprouts, clover sprouts, mung bean sprouts, all others)</li> <li>Salads from delicatessens and restaurants</li> </ul> |
| <b>Bread, grain, and cereal products</b><br> | <ul style="list-style-type: none"> <li>All breads, bagels, rolls, English muffins, muffins, pancakes, sweet rolls, waffles, French toast</li> <li>Potato chips, corn chips, tortilla chips, pretzels, popcorn</li> <li>Cooked grains and grain products, including pasta and rice</li> <li>All cereals, cooked and ready-to-eat</li> </ul>                                                                                       | <ul style="list-style-type: none"> <li>Raw (not baked or cooked) grain products (such as raw oats)</li> </ul>                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Beverages</b>                                                                                                                | <ul style="list-style-type: none"> <li>Boiled well water<sup>4</sup></li> <li>Tap water and ice made from tap water<sup>5</sup></li> <li>Commercially-bottled distilled, spring and natural waters<sup>6</sup></li> </ul>                                                                                                                                                                                                        | <ul style="list-style-type: none"> <li>Unboiled well water</li> <li>Cold-brewed tea made with warm or cold water</li> </ul>                                                                                                                                                                                                                                                                                                                                                                 |

<sup>4</sup> Bring tap water to a rolling boil and boil for 15 to 20 minutes. Store boiled water in the refrigerator. Discard water not used within 48 hours (2 days).

<sup>5</sup> See *Water Safety Guidelines* in “Food Safety Guidelines” for approved bottled water treatments.

<sup>6</sup> See *Water Safety Guidelines* in “Food Safety Guidelines” for approved bottled water treatments.

| Food groups                                                                                        | May eat                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Do not eat                                                                                                                                                                                                                                                                          |
|----------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Beverages</b>  | <ul style="list-style-type: none"> <li>• All canned, bottled and powdered beverages</li> <li>• Instant and brewed coffee and tea; cold brewed tea made with boiling water</li> <li>• Herbal teas brewed from commercially-packaged tea bags</li> <li>• Commercial nutritional supplements, both liquid and powdered</li> <li>• Commercially sterile ready-to-feed and liquid-concentrate infant formulas (avoid powdered infant formulas if a ready-to-feed or liquid concentrate alternative is available)</li> </ul> | <ul style="list-style-type: none"> <li>• Non-pasteurized fruit and vegetable juices</li> <li>• Maté tea</li> <li>• Kombucha</li> <li>• Wine, unpasteurized beer</li> <li>• Note: All alcoholic beverages should only be consumed following health care provider approval</li> </ul> |
| <b>Desserts</b>   | <ul style="list-style-type: none"> <li>• Refrigerated commercial and homemade cakes, pies, pastries and pudding</li> <li>• Refrigerated cream-filled pastries</li> <li>• Cookies, both homemade and commercially prepared</li> <li>• Shelf-stable<sup>1</sup> cream-filled cupcakes (such as Twinkies®, Ding Dongs®) and fruit pies (such as Pop-Tarts® and Hostess® fruit pies)</li> <li>• Canned and refrigerated puddings</li> <li>• Ices, popsicles and similar products</li> <li>• Candy, gum</li> </ul>          | <ul style="list-style-type: none"> <li>• Unrefrigerated cream-filled pastry products (not shelf-stable<sup>1</sup>)</li> </ul>                                                                                                                                                      |
| <b>Fats</b>     | <ul style="list-style-type: none"> <li>• Vegetable oils and shortening</li> <li>• Refrigerated lard, margarine, butter</li> <li>• Commercial, shelf-stable<sup>1</sup> mayonnaise and salad dressings including Blue Cheese and other cheese-based salad dressings (refrigerate after opening)</li> <li>• Cooked gravy and sauces</li> </ul>                                                                                                                                                                           | <ul style="list-style-type: none"> <li>• Fresh salad dressings (stored in the grocer's refrigerated case) containing raw eggs or cheeses listed as "Do Not Eat" under "Dairy"</li> </ul>                                                                                            |
| <b>Other</b>     | <ul style="list-style-type: none"> <li>• Commercial pasteurized Grade A honey<sup>7</sup></li> <li>• Salt, granulated sugar, brown sugar</li> <li>• Jam, jelly, syrups (refrigerate after opening)</li> <li>• Catsup, mustard, BBQ sauce, soy sauce, other condiments (refrigerate after opening)</li> <li>• Pickles, pickle relish, olives (refrigerate after opening)</li> <li>• Vinegar</li> </ul>                                                                                                                  | <ul style="list-style-type: none"> <li>• Raw honey; honey in the comb</li> <li>• Herbal and nutrient supplement preparations (refer to Guidelines for Use of Herbal and Nutrient Supplements)</li> <li>• Brewer's yeast, if uncooked</li> </ul>                                     |

<sup>7</sup> Honey products are not allowed for any child less than one year of age and not allowed for children with SCIDS until 9 months posttransplant.

## More nutrition tips

The chemotherapy your child will receive during his marrow or stem cell transplant will affect his nutrition in many ways. You may find that your child is not eating the way he normally does because of nausea, mouth and throat soreness, lack of appetite, or changes in the way foods taste. Use these tips to help you:

- Keep in mind that your child's calorie needs are higher during your transplant. Keep your child's body nourished even during the times he does not feel like eating.
- Your child will be using some medications that can be hard on his kidneys, so it is important to drink lots of fluids. Fluids include beverages, ice cream, sherbet, popsicles, Jell-O®, and soups. Your dietitian will give you a goal for daily fluid intake.
- Protein is needed for repair, growth, and fluid balance. Include high protein foods such as eggs, milk/dairy products, meat/poultry/fish, or medical nutrition supplements (such as Ensure®, Boost®, Scandishake®, Instant Breakfast®, NuBasics® or Resource®) as much as possible each day. Other foods such as beans, nuts, and pasta can add protein to your child's meals.
- Eat smaller, more frequent meals; snack often, and keep beverages handy at all times. Use a water bottle to keep beverages close all day long.
- Foods will probably taste differently for a while. This will pass, but your child may need to make some adjustments to the way he eats. Mix foods that taste bland with those that taste good. Drink beverages with meals or snacks if your mouth is dry. And remember, what does not taste good today might taste good tomorrow.
- Tell your doctor or nurse if your child is having nausea, vomiting, diarrhea, constipation, heartburn, or mouth and throat pain.
- A dietitian can answer questions you might have or help you find the foods and nutritional supplements that will work for your child.

## Shopping list

Below are some foods that may be easier to tolerate during and after chemotherapy. Circle the items your child enjoys and bring the list with you to the grocery store. If your child has high blood sugar (hyperglycemia), check with your dietitian or doctor to see which foods are right for your child.

### Beverages

- Carnation Instant Breakfast® drink\*
- Milk\*
- Chocolate milk\*
- Soda pop – caffeine free
- Sports drinks
- Kool-Aid
- Tang®
- Hawaiian Punch®
- Seltzers
- Assorted juices
- Cocoa
- Hot apple cider

### Cereals and breads

- Cream of Wheat®
- Cream of Rice®
- Cold cereals
- Muffins

### Cool treats

- Jell-O®
- Popsicles
- Sherbet/ice cream\*
- Yogurt\*
- Pudding\*

### Dairy/Meats

- Eggs\*
- Cottage cheese\*
- Cream cheese\*
- Thin sliced luncheon meats\*
- Assorted hard cheeses\*

### Fruits

- Canned fruits
- Fresh melons
- Applesauce

### Miscellaneous

- Mashed potatoes
- Macaroni and cheese\*
- Noodles\*
- Gravy

### Snacks

- Cheesecake\*
- Soft cookies
- Ritz® crackers
- Saltines
- Canned or instant soups
- Graham crackers
- Dinner rolls

\*good protein sources

**Tips on eating if you have thick, viscous saliva:**

- Switch to mostly fluid foods.
- Drinking more total fluids will help to loosen mucous.
- Club soda, seltzer, hot tea with lemon, or sucking on lemon drops may help to break up the mucous.
- Milk and dense liquids are sometimes hard to swallow when there is excess mucous.
- If you have nausea in the morning from mucous build up, try eating a lighter breakfast.
- Avoid thick nectars and juices, cream soups, and bread products.

**Some foods to try:**

| <b>Beverages</b>                                                                                                                                                | <b>Proteins</b>                                                                                                                |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|
| Fruit-ades, Kool-Aid®, popsicles, frozen ices<br>Slushies<br>Canned pops, lemonade, tea with lemon<br>Clear broth soups<br>Sugar-free lemon drops, sour candies | Moist, cooked fish and chicken<br>Thin, broth-based soups                                                                      |
| <b>Breads and cereals</b>                                                                                                                                       | <b>Fruit and vegetables</b>                                                                                                    |
| Hot cereals thinned with milk or water                                                                                                                          | Blended fruits or vegetables diluted to a thin consistency<br>High moisture fruits such as melon<br>Diluted nectars and juices |

### Tips on eating if your mouth and throat are sore:

- A soft, bland diet will cause less irritation.
- Avoid rough, acidic, and spicy foods.
- Popsicles and slushies (frozen beverages) may help to soothe your mouth and throat and quench your thirst.
- Try smaller bites of foods that don't take much chewing.
- Avoid extreme hot and cold food temperatures.
- Canned fruits are usually softer than fresh, raw fruits and cause less discomfort.

### Some foods to try:

| Beverages and seasonings                                                                                                                  | Proteins                                                                                                                                                                                                               |
|-------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Fruit-ades, Kool-Aid®, popsicles<br>Slushies<br>Low-salt homemade or canned soups<br>Herbs for seasoning: thyme, basil, oregano, bay leaf | Blended meats and casseroles<br>Bland entrees: macaroni and cheese, soufflés, bland quiches, creamed chicken, spaghetti with cream sauce<br>Baby foods<br>Milk<br>Eggnog<br>Cream pies, cheesecake<br>Custard, pudding |
| Breads and cereals                                                                                                                        | Fruit and vegetables                                                                                                                                                                                                   |
| Hot cereal; may be thinned with milk<br>Dry cereals soaked in milk<br>Plain cooked pasta<br>Mashed potatoes with butter                   | Cool fruits, especially watermelon, honeydew, grapes, papaya<br>Canned fruits, blended if needed<br>Pureed baby fruits<br>Diluted fruit nectars<br>Cold blended homemade soups: cucumber, avocado, potato              |

**Tips on eating if your mouth is dry:**

- Dry foods like meats and breads will be easier to swallow if served in a liquid, such as gravy or broth.
- Dip cookies in milk or cocoa, or eat with ice cream.
- Pour sauces over cake and gravy over breads.
- Citric acid, found in citrus fruits and fruit juices, may help to stimulate saliva; try adding lemon to tea, water, and soda.
- Do not eat dry crackers, unless dipped in broth or gravy.
- Do not eat really hot foods.
- Keep beverages handy when eating any food to keep your mouth moist between bites.

**Some foods to try:**

| <b>Beverages and other items</b>                                                                                                                                        | <b>Proteins</b>                                                                                                                                                        |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Beverages with meals<br>Tea with lemon, lemonade<br>Sherbet<br>Sugarless<br>Sugar-free sour candies<br>Biotene® gum, toothpaste, mouth rinse<br>Oral Balance® mouth gel | Tender, moist fish and chicken with<br>gravy or sauce<br>Casseroles<br>French dip sandwiches<br>Milk, milkshakes, malts<br>Eggnog<br>Cream pies, cheesecake with sauce |
| <b>Breads and cereals</b>                                                                                                                                               | <b>Fruit and vegetables</b>                                                                                                                                            |
| Cooked cereals<br>Dry cereals soaked in milk                                                                                                                            | Vegetables with sauces<br>Melon, peaches<br>Canned fruits<br>Fruit juices and nectars                                                                                  |

## Calorie and protein guide

For calorie and protein information, ask your dietitian for the booklet, "A Guide to Good Nutrition."

## Food records

Follow these steps:

- Use a new food record sheet each day (you can ask for more records from your dietitian).
- Record your child's name and date.
- Do not write in the "Code" columns.
- Write down the time your child eats or drinks each food.
- Note if the food is vomited up and what time.
- Turn the food record over and answer the questions on the back.
- Bring your completed food record sheet to each nutrition appointment, every time you come for a blood draw, and for every clinic appointment.

How to record fluids on your food record:

- Include water, juice, milk, soup, ice cream, sherbet, Jell-O®, Kool-Aid®, soda, and yogurt.
- Record fluids as cups, ounces (oz.), or milliliters (mL).
- Describe drinks clearly, such as: 2% milk or whole milk.
- Specify how much sugar you add when sweetening tea or other drinks.
- List each ingredient of special drinks (such as homemade milkshakes).

How to record solid foods on your food record:

- Cereal: Measure with a measuring cup. Include the amounts of milk and sugar added. State if milk is used in the preparation of cooked cereals.
- Condiments and snacks: Include these, as they are important sources of calories. Please write them out on your record! Be specific about the amount you use (1 teaspoon, 2 tablespoons, and so on).

Examples are:

- Butter or margarine (on toast, sandwiches, potatoes, oatmeal, etc.)
- Mayonnaise or salad dressing
- Syrup, jam, or honey
- Olives or pickles
- Nuts or sunflower seeds
- Potato chips or other kinds of chips
- Fruits and vegetables: State whether fresh or canned. Measure cooked ones with a measuring cup or state number (such as 3 French fries). Estimate raw foods, such as "one medium tomato" or "3 carrot sticks" or "½ large banana."
- Meat, cheese, and eggs: State how meat or eggs are prepared (fried, roasted, broiled, and so on). State whether you eat the skin of poultry.
- List portion size by the dimension or cup: 1 hamburger patty, 3" diameter x 1/2" thick; 1/4 cup grated cheddar cheese.
- Some foods can be listed by the piece: 1 scrambled egg, 1 small chicken thigh without skin, 5 potato chips

How to record soups:

- State whether homemade, canned, or dehydrated. State if creamed soups are made with milk or water.

How to record mixed items:

- List recipes for casseroles, pasta dishes, sandwich ingredients, and contents of tacos, pizzas, hamburgers, and hotdogs.

How to record special products, frozen dinners, and so on:

- Tape onto your food record the nutrient information from TV dinners, protein powders, canned foods, or other products with which we may not be familiar.

How to record brand names foods:

Include these, as the brand name can be helpful. Examples are:

- $\frac{3}{4}$  McDonald's Big Mac®
- 1.6 oz Butterfinger® candy bar

How to record food when eating out:

- State fast food or restaurant names and the foods and beverages you eat.

## Herbal and nutrient supplements

Your child may be using nutrient supplements or herbal preparations. Your dietitian and doctor will ask about any supplements or herbals your child uses during their initial evaluation. **Stop use** of all herbal and nutrient supplements at this time. These supplements may affect treatment or even cause a serious infection.

There are four main concerns about the use of nutritional supplements, herbals, and other preparations during marrow or stem cell transplantation or high dose chemotherapy:

1. Interactions between herbal supplements and prescribed medications may reduce the effectiveness of drugs routinely used during transplantation or chemotherapy.
2. Potential contamination of preparations derived from plants may cause bacterial, fungal, or parasitic infections because of inadequate purification and sterilization. Even boiling water may not destroy some infectious organisms that can contaminate these products.
3. A few specific preparations have been repeatedly associated with serious toxic side effects to the liver, blood, kidneys, heart, and other body organs.
4. The production, distribution, and labeling of herbal preparations and nutrient supplements are not regulated by the U.S. Food and Drug Administration. As a result, the dosage may vary from the dose listed on the label. Also, the product might contain ingredients not listed on the label.

## Herbal and botanical preparations

Herbal and botanical preparations include a variety of products derived directly from plants. They may be sold as tablets, capsules, liquid extracts, teas, powders, and topical preparations. There are no manufacturing regulations for the cleanliness or purity of these products. There is a danger the products may be contaminated with fungus, bacteria, parasites or other chemicals, which can be life-threatening to a person with an impaired immune system, including persons receiving chemotherapy or transplantation. Even boiling water may not kill some organisms that can contaminate these products.

It is recommended that your child avoids all herbal and botanical products during chemotherapy and as long as her immune system is impaired. Make the decision to use any preparation with your doctor, who will consider how the product affects your child's kidneys, liver, and other organs, your child's risk of infection, and any interactions it may have with other medications.

Some herbals may decrease blood clotting. If your child has low platelet counts, do not take garlic and ginkgo biloba. Do not use any product that is given as an injection into the central line or as an injection under the skin. Several herbal and botanical medications have very dangerous side effects and should not be taken under any circumstance. These include:

- |                 |                          |                           |                         |
|-----------------|--------------------------|---------------------------|-------------------------|
| • Alfalfa       | • Dieter's Tea (senna,   | • Kava kava               | • Pennyroyal            |
| • Borage        | aloe, rhubarb root,      | • Laetrile (apricot pits) | • Sassafras             |
| • Chaparral     | buckthorn, cascara,      | • Licorice root           | • St. John's Wort       |
| • Chinese herbs | castor oil)              | • L-tryptophan            | • Yohimbe and yohimbine |
| • Coltsfoot     | • Ephedra or MaHuang     | • Lobelia                 |                         |
| • Comfrey       | • Groundsel or Life Root | • Maté tea                |                         |
| • DHEA          | • Heliotrope or Valerian | • Pau d'arco              |                         |

## Vitamin and mineral supplements and antioxidants

Your child will be prescribed a multiple vitamin and mineral supplement that provides nutrients at about the same levels of the Dietary Reference Intakes (DRI). In some instances, you may wish that your child takes higher doses of specific vitamins, minerals, or antioxidants. While higher doses are not suggested, the following is a list outlining the DRI and maximum amounts of supplements recommended. Higher doses may be toxic or interact with other medications.

| Micronutrient                             | Dietary Reference Intakes                 | Safe upper limits                                                                                             |
|-------------------------------------------|-------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| <b>Vitamin A</b>                          | 2700 to 3000 IU/<br>800 to 1000 RE or mcg | No more than 10,000 IU or 3,000 mcg.                                                                          |
| <b>Vitamin C (ascorbic acid)</b>          | 120 mg                                    | No more than 500 mg.                                                                                          |
| <b>Vitamin D (calciferol)</b>             | 200 to 600 IU or 5 to 15 mcg              | No more than 2000 IU or 50 mcg.                                                                               |
| <b>Vitamin E (tocopherol)</b>             | 8 to 10 mg or IU                          | No more than 100 mg or IU while on anticoagulant therapy. No more than 800 mg or IU.                          |
| <b>β-carotene</b>                         | No DRI                                    | No more than 25,000 IU or 15 mg.                                                                              |
| <b>Folic acid (folate)</b>                | 400 mcg                                   | No more than 1000 mcg or 1 mg.                                                                                |
| <b>Vitamin B<sub>1</sub> (thiamin)</b>    | 1.1 to 1.2 mg                             | While high intakes of B-vitamins may not be toxic, talk with your dietitian to discuss your particular needs. |
| <b>Vitamin B<sub>2</sub> (riboflavin)</b> | 1.1 to 1.3 mg                             |                                                                                                               |
| <b>Niacin (mg of niacin equivalents)</b>  | 14 to 16 mg                               | No more than 35 mg.                                                                                           |
| <b>Vitamin B<sub>6</sub> (pyridoxine)</b> | 1.3 to 1.7 mg                             | No more than 100 mg.                                                                                          |
| <b>Vitamin B<sub>12</sub> (cobalamin)</b> | 2.4 mg                                    | While high intakes of B-vitamins may not be toxic, talk with your dietitian to discuss your particular needs. |
| <b>Biotin</b>                             | 30 mcg                                    |                                                                                                               |
| <b>Pantothenic acid</b>                   | 5 mg                                      |                                                                                                               |
| <b>Iron</b>                               | 12 to 15 mg                               | Iron supplementation is not recommended post-transplant.                                                      |
| <b>Selenium</b>                           | 40 to 70 mcg                              | No more than 200 mcg.                                                                                         |
| <b>Calcium</b>                            | 1000 to 1200 mg                           | No more than 2500 mg.                                                                                         |

## Recommended vitamin brands

Note: vitamin brands that contain iron and/or extra vitamin C are not recommended.

- One-a-Day 50 Plus®
- Nature Made Mature Balance®

## Antioxidants

A high intake of some antioxidants (vitamin C, vitamin E, and  $\beta$ -carotene) may protect against the development of certain types of cancer. However, taking antioxidant supplements during radiation and chemotherapy may reduce the effectiveness of these treatments in destroying diseased cells. Therefore, your child should stop antioxidant supplementation before chemotherapy and radiation. Antioxidants may be inappropriate post-transplant because of interactions with medications, immunosuppressive therapy, or other vitamins and minerals in your child's body.

## B vitamins

The B vitamins (thiamin, niacin, riboflavin, pyridoxine (B<sub>6</sub>), folate, cobalamin (B<sub>12</sub>), biotin, and pantothenic acid) are water-soluble nutrients that assist in energy production. High levels of supplementation may not be toxic. However, it is important to maintain a balance among these B-vitamins. High doses of one may have a negative effect.

## Specific recommendations

As your child's immune system begins to recover and strengthen, he may be able to include herbal supplements and vitamins in his diet, depending on the type of transplant he had. Some people wish to start using the supplements they were taking before transplant. **It is critical to check with your child's health care team before taking any vitamin or herbal supplement, as some may put his still immature immune system at risk.**

## Allogeneic transplantation

Your child is at risk for infections until all immunosuppressive medications have been stopped and is free of active chronic GVHD (graft versus host disease). Immunosuppressive medications include cyclosporine, tacrolimus (FK-506®), prednisone, thalidomide, Imuran®, Rapamycin®, mycophenolate mofetil (MMF, CellCept®) and interferon.

# Central line care

## What is a central venous catheter?

A central venous catheter, or a central line, is a small flexible tube inserted into a large vein in your child's chest. It is used to give your child fluid, nutrients, medicine, and blood products. It is also used to get blood samples without having to draw blood from your child's arm. Many types of central venous catheters are available; they may be called tunneled catheters, central venous lines, and Hickman lines.

## Central venous catheter placement: what to expect

The insertion of the central line is a minor surgical procedure. It is done in an operating room under general anesthesia (full sleep) and takes about one hour. The catheter is threaded through a "tunnel" under the skin and then placed into a large vein in the chest near the neck that returns blood to the heart. A small cuff on the catheter helps hold it in place in the tunnel, underneath the skin. This cuff also acts as a barrier to help prevent bacteria on the skin from traveling up the catheter tunnel and into the bloodstream. Your child will likely have a few sutures in place to help secure the line. Your child's shoulder and chest area may be sore for a few days after insertion, for which a mild pain reliever will be prescribed. It is helpful for your child to move the shoulder and neck right after surgery to help keep the area from getting stiff.

Your child's nurse will teach you how to care for the central line catheter by the day before it is inserted, and you will perform the first dressing change with the nurse's help the day after the catheter is inserted.

## How is the procedure done?

1. The doctor will make two small incisions, one in the upper chest near the neck and the other on the lower chest.
2. Between these incisions, your child's doctor will make a tunnel under the skin.
3. The catheter will be inserted in the lower incision on the chest and pulled through the tunnel.
4. The catheter is inserted into the large chest vein located near the neck (this vein returns blood to the heart).

## Things to remember:

- Secure the line by dressing your child in a tight-fitting tank top or sports bra for at least one night after placement is recommended.
- Do not give your child aspirin, ibuprofen, or other over-the-counter pain medications without first checking with your child's doctor or nurse.
- No heavy lifting for 72 hours.

## Activity

Routine light exercise, sports, sleep, and travel are not limited by having a central line. The dressing is changed depending on dressing type or any time the dressing gets wet. Avoid swimming pools and hot tubs. Do not allow the blue caps of the catheter to float in bath water. Do not submerge any part of the catheter in bath water. The most important thing to remember about the line during activity is to always attach the catheter to skin, clothing, or a necklace to prevent accidental dislodgement. You may use a "bulldog" clamp to attach it to clothing or tape the catheter to the skin. Remember that the "bulldog" is an emergency clamp and should be kept with your child at all times.

## Catheter care at a glance

| Dressing options                             | Dressing change | Flushing               | Tape tabs | Alcohol wipe | Parafilm®    | AquaGuard®   |
|----------------------------------------------|-----------------|------------------------|-----------|--------------|--------------|--------------|
| Occlusive dressing with or without Biopatch® | every 7 days    | daily or with each use | daily     | daily        | with bathing | with bathing |
| Gauze and tape                               | daily           | daily or with each use | daily     | daily        | with bathing | with bathing |

## Fast facts on central line care: how to protect your child's catheter

| Do                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>• Keep dressing supplies dry—away from the bathroom and kitchen.</li> <li>• Secure your child's catheter and prevent accidental removal of the line. There are many ways to do this: <ul style="list-style-type: none"> <li>○ Place plastic tape tabs between clamp and cap on the catheter and change daily. Use the plastic tape tabs and bulldog clamp to secure the catheter to clothing or a necklace.</li> <li>○ Place catheter in a clean, cloth pouch and secure the pouch with a bulldog clamp to clothing or a necklace.</li> <li>○ Coil the catheter over the exit site and tape it to the skin.</li> </ul> </li> <li>• Place catheter clamps on the thick, reinforced area of the line, not too close to the hard plastic portion of the line.</li> <li>• Change the dressing if it is wet, if it starts to come off, or if there is moisture underneath the dressing.</li> <li>• Clean your child's line once a day with alcohol swabs and replace plastic tape tabs.</li> <li>• When bathing or showering, you should always cover the exit site of your child's catheter with a plastic covering such as AquaGuard® or plastic wrap to prevent tap water from entering the catheter tunnel. The uncovered exit site should not come in contact with tap or bath water.</li> <li>• Always securely wrap the Clave® end caps with Parafilm® to prevent water from entering the Clave® top or into the connection to the catheter.</li> <li>• Change your child's dressing if you notice moisture under the dressing when removing the plastic covering and Parafilm®. If you notice moisture under the Parafilm®, ask to have your child's Clave® caps changed in the clinic.</li> <li>• When changing your child's dressing, if build-up is noted, you may first cleanse skin around the exit site with a sterile, saline-soaked gauze pad to remove Chloraprep One Step® (chlorhexidine) and the no-sting barrier. Never use tap water to cleanse the exit site.</li> <li>• <b>Keep your child's bulldog clamp with you at all times. The bulldog clamp is a <u>safety</u> clamp. Clamp the catheter close to their chest and call the clinic immediately if the catheter leaks, gets cut, or breaks.</b></li> </ul> |
| Don't                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <ul style="list-style-type: none"> <li>• Do not take the Clave® cap connectors off of your child's catheter.</li> <li>• Do not tape over the connection between Clave® caps and catheter.</li> <li>• Do not let your child swim or use a hot tub.</li> <li>• Do not allow Clave® caps, central catheter, or exit site to be submerged in bath water.</li> <li>• Do not store catheter supplies in the bathroom or kitchen.</li> <li>• <b>Do not use scissors near your child's catheter.</b></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |

### Daily care: when to flush and what solution to use

- Flush each line of the catheter with normal saline followed by a heparin solution at least once each day and after each use.
- If your child is having a blood draw, both lines of the catheter will be flushed at that time unless the side not used for blood draw is connected to IV tubing.
- Flush the catheter at the beginning of an infusion with normal saline only.
- Flush the catheter at the end of an infusion with normal saline followed by a heparin solution.
- **If your child is receiving antibiotics:** Your doctor may recommend that they alternate infusing antibiotic doses between all lumens of the catheter. Please check with your child's nurse if you have any questions.

### Anti-coagulation therapy for your child's catheter

**Heparin** is used to flush your child's catheter to prevent clot growth within the central line. You will flush each lumen of the catheter with normal saline and heparin lock flush solution at least once a day. The daily heparin catheter flush is still required even if your child is on any of the oral or injectable blood thinners listed below to prevent or treat a blood clot.

In addition to heparin flushes, your child may also be required to take other medications to prevent clotting such as:

- **Warfarin (Coumadin®)** is given orally to prevent or treat clotting within or around your child's central line or to treat blood clots that have formed in other blood vessels. Your child will have their blood levels drawn throughout their treatment to make sure that the clots are treated appropriately.
- **Low-molecular weight heparin**, such as enoxaparin (Lovenox®), tinzaparin (Innohep®), dalteparin (Fragmin®), or fondaparinux (Arixtra®; which is not a heparin or low-molecular weight heparin). Your child will be prescribed only one of the low-molecular weight heparin medications or Arixtra® at any one time. Your child will receive a shot/injection under the skin 1 to 2 times each day. Your child will have blood levels drawn periodically to check for anti-coagulation activity to ensure that they are treated appropriately.

**Heparin "allergy" or history of heparin-induced thrombocytopenia (HIT):** If you have ever been told that your child has an allergy to heparin, they should not use heparin or low-molecular weight heparin to prevent clots. This includes using heparin to flush the catheter. If your child has a heparin allergy, please ask about other flushing options. Please discuss with your child's doctor or nurse if you are unsure if your child has a heparin allergy.

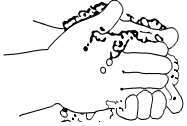
## How to flush the catheter

Flush each line of the catheter at least once each day and after each use, first with saline, then with heparin.

Supplies needed:

- Two - 10 ml syringes with normal saline flush
- Two - 5 ml syringes with heparin lock flush solution
- Alcohol wipes

1. Wash your hands.



2. Remove the syringe(s) from their package(s) by peeling the plastic downward.



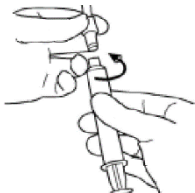
3. Put on clean gloves. Vigorously scrub the top of the Clave® cap with an alcohol wipe for 15 seconds using a twisting motion as if you were juicing an orange. Allow the Clave® to dry completely for at least 5 seconds.



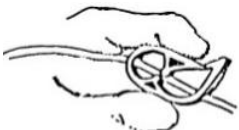
4. Hold the syringe with the cap on, pointed towards the ceiling, and remove the cap from the syringe. Carefully remove the air bubble by gently pulling back on the syringe to release pressure and then pushing up on the plunger until all air is removed from the syringe.



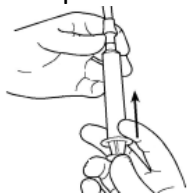
5. Insert the syringe into the center of the Clave® cap by pushing in and turning toward the right. Be sure not to touch the end of the Clave® cap or end of the syringe with your hand. The syringe tip should only touch the cleansed end of the catheter cap. If in doubt, please throw it out.



6. Unclamp the catheter.



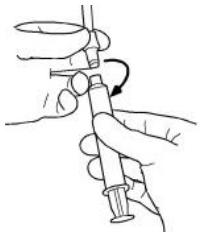
7. Flush first with 5ml of normal saline followed by 2.5ml of heparin. Push the plunger on the syringe with alternating pressure and release (starting and stopping to create turbulence) to inject the fluid into the catheter. This keeps the catheter clean. Do not flush all of the fluid into the catheter. Only flush 5 ml of normal saline and 2.5 ml of heparin.



9. To create positive pressure in the line, clamp the catheter while injecting the last of the fluid before removing the syringe.



10. Remove the syringe. Discard in regular garbage can.



11. Repeat steps 2 through 10 on the other line. Use separate syringe for flushing each side of the central line.

### Daily care: cleaning the catheter

It is important to clean your child's catheter every day. This helps to prevent infection.

1. Remove plastic tape tabs near Clave® caps.
2. Using two alcohol wipes for each line (one to hold the line and one to wipe it), start where line exits the dressing and wipe towards the end of the line. Take special care to thoroughly scrub around the connection between the line and the Clave® caps.
3. Replace plastic tape tabs near Clave® caps.

If you are using a baby bootie or cloth bag to hold your line, please be sure to use a freshly laundered bag after you clean your line. Make sure to change it daily.

Remember to clean your child's catheter every day.

### When to change your child's dressing

**If your child has a Biopatch® and occlusive dressing:**

- Change the dressing every 7 days.

**If your child has a transparent occlusive dressing:**

- Change dressing every 7 days.

**If your child has a gauze and tape dressing:**

- Dressing should be changed daily.

### **Additional dressing change tips:**

- Both dressing and exit site should be looked at each day.
- Talk to the nurse if your child's skin is sensitive to the dressing.
- The dressing should also be changed if:
  - The exit site cannot be seen because of drainage or moisture.
  - The dressing starts to come off.

### **Dressing change supplies**

Wash your hands with soap and water. Assemble your supplies on a clean workspace:

#### **If your child has a Biopatch® and occlusive dressing:**

- 1 package 2x2 gauze
- Biopatch®
- 1 ChloraPrep One-Step® application
- 2 pairs of clean gloves
- Sterile saline flush
- 2 alcohol wipes
- 2 Cavilon No-Sting Barrier Film® foam pads
- Transparent dressing (IV3000, Sorbaview, Tegaderm™ HP)
- Plastic tape

#### **If your child has a transparent occlusive dressing:**

- 1 package 2x2 gauze
- Transparent dressing (IV3000, Sorbaview, Tegaderm HP)
- 1 ChloraPrep One-Step® application.  
\*If allergic to chlorhexidine, use 1 package isopropyl alcohol swab sticks and 1 package povidone-iodine swabs stick.
- 2 pairs of clean gloves
- Sterile saline flush
- 2 alcohol wipes
- 2 Cavilon No-Sting Barrier Film® foam pads
- Plastic tape

#### **If your child has a gauze and tape dressing:**

- 3 packages 2x2 gauze (or 1 package 2x2 split gauze and 2 packages 2x2 gauze)
- 2 alcohol wipes
- Sterile saline syringe
- Skin prep
- Paper tape
- 1 ChloraPrep One-Step® application  
\*If allergic to chlorhexidine, use 1 package isopropyl alcohol swab sticks and 1 package povidone-iodine swabs stick.
- 2 pairs of clean gloves
- Plastic tape (for tape tabs)

### **Dressing change steps**

1. Wash your hands with soap and water again.
2. Put on a clean pair of gloves.
3. Remove old dressing and throw away.

#### **If your child has an occlusive dressing with Biopatch®:**

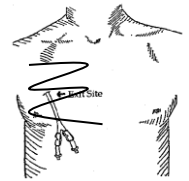
- Remove the transparent dressing by starting at a corner, pulling "low and slow." When the Biopatch® is reached, continue to slowly pull back on the dressing to separate the Biopatch from the transparent dressing. **Do not use scissors.**

#### **If your child has an occlusive transparent dressing:**

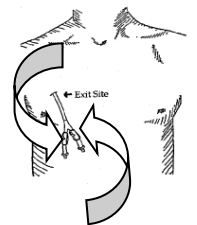
- Remove the transparent dressing by starting at a corner, pulling "low and slow." **Do not use scissors.**

**If your child has a gauze and tape dressing:**

- Remove the old gauze and tape dressing. **Do not use scissors.**
4. Remove plastic tape tabs near Clave® caps and throw away.
  5. Open gauze pad and wet the pad with saline from the syringe. **Do not set a wet gauze pad on any surface or it will become dirty.**
  6. Gently wipe skin in all directions around exit site with the saline-soaked gauze pad, allow to dry. This will remove any buildup of Chloraprep® and No-Sting Barrier® film and will also decrease skin irritation. Throw away gauze.
  7. Report to your nurse if there is:
    - Bleeding or drainage at the catheter site.
    - Redness or swelling at the catheter site.
    - Pain or discomfort at the catheter site.
  8. Take off gloves and throw them away.
  9. Wash your hands again.
  10. Put on a second pair of clean gloves.
  11. If crust is present, clean it from catheter exit site, using an alcohol wipe if necessary. If this is a scab, you do not need to remove it.
  12. Clean around catheter exit site with ChloraPrep One-Step® swab using a back-and-forth motion across the exit site for 30 seconds. Allow to dry completely for 1 to 2 minutes. **The chlorhexidine used while cleaning the catheter exit site should be completely dry before applying the Cavilon No-Sting Barrier Film®.**



**Alternate cleaning for chlorhexidine allergy:** Clean exit site in circular motion starting at the catheter and circle outward away from the exit site using one of the povidone-iodine swabs. Use the other two povidone swabs for a total of 3 cleanings at the exit site. Allow to air dry. Follow with 3 applications of alcohol swab sticks in the same pattern. Allow to air dry.



13. Open two alcohol wipe packages.
  - Using one alcohol wipe, hold the catheter near the exit site (near chest).
  - Using the second alcohol wipe, start where the line exits the skin and wipe the entire catheter.
14. Apply new plastic tape tabs.
15. Apply skin prep:  
**If your child has a Biopatch® and occlusive dressing:**

- Apply skin prep (Cavilon No-Sting Barrier Film®) to the area that will be under the transparent dressing. Avoid the exit site and the area that will be under the Biopatch®, as it will not be able to penetrate the skin and work to prevent an infection. Allow to dry completely for 1 to 2 minutes.

**If your child has a transparent occlusive dressing:**

- Apply skin prep (Cavilon No-Sting Barrier Film) to the site where the dressing will be placed.

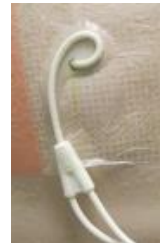
**If your child has a gauze and tape dressing:**

- Apply skin prep to area where paper tape will be applied– allow to dry completely.

16. Apply new dressing:

**If your child has a Biopatch® and occlusive dressing:**

- Place Biopatch® around catheter with the white side towards the skin (white to the bone, blue to the sky). The edges of the slit should touch each other to work best.
  - Do not place Biopatch® on top of catheter. If edges do not meet because catheter is too big or stitches are in the way, place the Biopatch® around the catheter making sure the Biopatch® is in contact with the skin.
  - To ensure easy removal, place Biopatch® so that the catheter rests on or near the slit.
  - Place the transparent dressing over the catheter.
- Optional:** make a loop with catheter to decrease the external length of the catheter.
- Paint the border of the transparent dressing with the Cavilon No-Sting Barrier® to create a seal between the dressing and the skin.
  - Write today's date on the dressing.
  - If the Biopatch® becomes swollen with fluid, water, or blood, or the dressing starts to come off, the dressing should be changed more frequently. Talk to your nurse if your child's skin is sensitive to the transparent dressing or if your child's dressing needs to be changed more often than once every 3 days.



**If your child has a transparent occlusive dressing:**

- Place transparent dressing over central line exit site.
- Optional:** make a loop with catheter to decrease the external length of the catheter.
- Paint the border of the transparent dressing with Cavilon No-Sting Barrier® to create a seal between the dressing and the skin.
  - Write today's date on the dressing.

**If your child has a gauze and tape dressing:**

- **If using folded gauze:** touching only the corner, remove one of the 2x2 gauze pieces, fold in half and place under the catheter.
- **If using split gauze:** Touching only the corners, place the 2 split gauze with the slits positioned horizontally (in opposite directions) around the central line as close as possible to where it exits the skin.
  - Place the second 2x2 over the line and gauze.
  - Secure gauze to skin with paper tape. Write the date and time on the dressing.
  - Talk to your child's nurse if the skin is sensitive to paper tape; an alternative tape may be suggested.



17. Secure the catheter by:

- Coiling it over the exit site and taping it to the skin,
- Placing in a clean cloth pouch and secure with a bulldog clamp.
- Using a bulldog clamp to attach the tape tab to your clothing or necklace.

## Protecting your child's central line when bathing or showering

1. Wash your hands.
2. Place Parafilm® on Clave® caps and tubing connections.

- First stretch the Parafilm®.
- Then wrap it around the Clave® cap connection on each side of the catheter (stretching it makes it stick to itself).
- Then flip it over the end of the catheter to cover the Clave® cap, using your fingers to twist and mold it around the catheter, with a spiraling-down technique.
  - Wrap only around the thicker part of the end of the catheter. The Parafilm® will fit closely around the connector and will stick to itself. Make a tab on the end so it will be easier to remove.



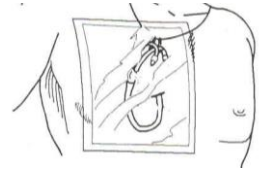
|                                                                                  |                                                                                  |
|----------------------------------------------------------------------------------|----------------------------------------------------------------------------------|
| <b>PARAFILM</b><br><b>"M"</b><br>Laboratory Film<br><i>American National Can</i> | <b>PARAFILM</b><br><b>"M"</b><br>Laboratory Film<br><i>American National Can</i> |
| <b>PARAFILM</b><br><b>"M"</b><br>Laboratory Film<br><i>American National Can</i> | <b>PARAFILM</b><br><b>"M"</b><br>Laboratory Film<br><i>American National Can</i> |

The Parafilm® will be pre-cut to the correct size. Approximately two rows of two squares side by side will be needed for each side of your child's catheter.



3. Cover the entire dressing with a square of AquaGuard® (approximately 9x9). You may place the entire catheter under the AquaGuard®. If you do, the catheter tips must still be covered with Parafilm®.

**\*Alternatively, plastic wrap may also be used in place of AquaGuard® and tape with paper tape on all sides.**



4. If your child takes a bath, the catheter should be kept above the water level at all times. If your child showers, the dressing should be kept out of the direct stream of water.
5. After bathing, dry off the plastic wrap or AquaGuard® with a towel, then remove it and throw it out.
6. Remove Parafilm® from Clave® caps – **do not use scissors**.
7. Replace the dressing if there is moisture underneath or it has become loose.

## Troubleshooting problems for the central venous catheter

Note: If the below solutions don't solve your problem, call SCCA or the after-hours for additional instructions.

| Problem                                                                                                                                                                                                     | Solution                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Line does not flush.</b>                                                                                                                                                                                 | 1. Check to see if catheter is clamped or kinked.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Fluid is leaking from the catheter. Do not use scissors near your child's line.</b> Catheter may be cut accidentally if dressing is removed with scissors.                                               | <ol style="list-style-type: none"> <li>1. Immediately place a bulldog clamp on the catheter as close to the chest as possible.</li> <li>2. Check the catheter to find the break. It can be as small as a pinhole.</li> <li>3. Clean the break with an alcohol wipe.</li> <li>4. Wrap a sterile 2x2 gauze or an alcohol wipe around the break in the catheter and tape it in place.</li> </ol>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Clave® cap comes off catheter.</b>                                                                                                                                                                       | <ol style="list-style-type: none"> <li>1. Immediately clamp catheter. <b>Do not replace cap.</b></li> <li>2. Scrub catheter end with alcohol for 15 seconds and let dry 5 seconds.</li> <li>3. Place sterile saline syringe on end of catheter. <b>Do not flush.</b></li> </ol>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Swelling around the exit site or fluid leaking from exit site.</b><br>Swelling of the exit site, or bloody drainage or fluid leaking from the exit site can be a sign that the catheter is out of place. | <ol style="list-style-type: none"> <li>1. Stop any fluids running into the catheter.</li> <li>2. Place an ice pack on the swollen area, do not apply directly to bare skin</li> </ol>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Swelling of the neck and face.</b><br>Swelling of the neck and face can be a symptom of the catheter being out of place or that the vein is obstructed.                                                  | <ol style="list-style-type: none"> <li>1. Stop any fluids running into the catheter.</li> </ol>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Air in the catheter, the child is not short of breath.</b> This could be caused by air being accidentally injected into the catheter or the Clave® cap falling off when the line is not clamped.         | <ol style="list-style-type: none"> <li>1. Check the clamp to make sure that it is closed and then wash hands.</li> <li>2. Open two pre-filled saline syringes and one pre-filled heparin lock flush syringe.</li> <li>3. Scrub the end of the catheter cap with alcohol for 15 seconds and let dry 5 seconds.</li> <li>4. Attach one of the pre-filled saline syringes.</li> <li>5. Unclamp the line.</li> <li>6. <b>Pull back</b> on the syringe until blood appears.</li> <li>7. Clamp the line and discard the syringe.</li> <li>8. Scrub the end of the catheter cap with alcohol for 15 seconds and let dry for 5 seconds.</li> <li>9. Flush the catheter as usual, making sure to close the clamp at the end of the flush. If the clave cap is not on the line, leave the syringe attached.</li> <li>10. If your child becomes short of breath, call 911. Call Clinic if Clave® Cap is off.</li> </ol> |
| <b>Air in the catheter, and your child SUDDENLY becomes SHORT OF BREATH, DIZZY, OR CONFUSED.</b>                                                                                                            | <ol style="list-style-type: none"> <li>1. Have your child lie down on their left side so that their right hip is lifted above the level of the heart while checking the clamps on the catheter to be sure they are closed.</li> <li>2. Call 911 for emergency assistance.</li> <li>3. Tell the medics to take your child to Seattle Children's.</li> <li>4. Call SCCA or the after-hours clinic to tell them that your child is going to the ER via ambulance.</li> </ol>                                                                                                                                                                                                                                                                                                                                                                                                                                    |

## Overview of medications

| <b>Anti-infectives</b>                                     |                                        |                                                                                               |
|------------------------------------------------------------|----------------------------------------|-----------------------------------------------------------------------------------------------|
| Ceftriaxone (Rocephin®)                                    | Prevent and treat bacterial infections | Given intravenously                                                                           |
| Levofloxacin (Levaquin®)                                   | Prevent and treat bacterial infection  |                                                                                               |
| Ciprofloxacin (Cipro®)                                     | Prevent and treat bacterial infections |                                                                                               |
| Dapsone                                                    | Prevent pneumocystis pneumonia         |                                                                                               |
| Trimethoprim/<br>Sulfamethoxazole<br>(Bactrim® or Septra®) | Prevent pneumocystis pneumonia         | May cause white blood cell (WBC) counts to drop                                               |
| Vancomycin (Vancocin®)                                     | Treats bacterial infections            |                                                                                               |
| Acyclovir/valacyclovir<br>(Zovirax®, Valtrex®)             | Prevents and treats viral infections   | Taken for one year post transplant                                                            |
| Fluconazole (Diflucan®)                                    | Prevent fungal infections              | Taken until day +75 or off prednisone                                                         |
| Foscarnet (Foscavir®)                                      | Treats cytomegalovirus (CMV)           | May cause electrolyte imbalances and reduced kidney function needing intravenous fluids (IVF) |
| Ganciclovir (Dhpg)<br>(Cytovene®)                          | Treats CMV                             | May cause WBC to drop                                                                         |
| <b>Anti-Nausea (Antiemetics)</b>                           |                                        |                                                                                               |
| Diphenhydramine<br>(Benadryl®)                             | Prevent and treat nausea               | Also treats allergic reactions, causes drowsiness                                             |
| Granisetron (Kytril®)                                      | Prevent and treat nausea               | Used mostly with chemotherapy treatment                                                       |
| Lorazepam (Ativan®)                                        | Prevent and treat nausea               | Also relaxes, causes drowsiness                                                               |
| Ondansetron (Zofran®)                                      | Prevent and treat nausea               | Used mostly with chemotherapy treatment                                                       |
| Prochlorperazine<br>(Compazine®)                           | Prevent and treat nausea               |                                                                                               |
| <b>Graft-versus-host disease (GVHD)</b>                    |                                        |                                                                                               |
| Cyclosporine<br>(Sandimmune®)                              | Prevent and treat GVHD                 | Take with food, drink lots of fluid, may cause decreased kidney function and magnesium loss   |
| Tacrolimus (Prograf®)                                      | Prevent and treat GVHD                 |                                                                                               |
| Mycophenolate mofetil<br>(CellCept® Or MMF)                | Prevent and treat GVHD                 |                                                                                               |
| Prednisone (Deltasone®)                                    | Prevent and treat GVHD                 | Never take on an empty stomach, may cause increased blood sugar                               |

| <b>Supplements</b>               |                                                                 |                                              |
|----------------------------------|-----------------------------------------------------------------|----------------------------------------------|
| Magnesium oxide (MagOx®)         | Supplement magnesium                                            | May cause loose stools                       |
| Multivitamins                    | Supplement vitamins                                             | Take when off TPN (total parental nutrition) |
| Potassium (k-dur® Klor-con®)     | Supplement potassium                                            | Take with food                               |
| <b>Additional medications</b>    |                                                                 |                                              |
| Amlodipine (Norvasc®)            | Treat high blood pressure                                       |                                              |
| Atenolol (Tenormin®)             | Treat high blood pressure                                       |                                              |
| Conjugated estrogens (Premarin®) | Supplement estrogen in the body, control menstrual bleeding     |                                              |
| Medroxyprogesterone (Provera®)   | Supplement progesterone in the body, control menstrual bleeding |                                              |
| Heparin (Hep-Pak®)               | Flush for Hickman catheter to prevent clotting                  |                                              |
| Warfarin (Coumadin®)             | Prevent blood clot from forming                                 |                                              |
| Enoxaprin (Lovenox®)             | Prevent blood clot from forming                                 | Given as an injection                        |
| Lactase (Lactaid®)               | Aids in digestion of milk products                              | Take before milk products                    |
| Omeprazole (Prilosec®)           | Decrease stomach acid production                                |                                              |
| Ursodiol (Actigall®, Urso®)      | Prevent liver problems                                          |                                              |

## Cyclosporine

Cyclosporine is an immune-suppressing drug used to treat or prevent graft versus-host disease (GVHD) in bone marrow transplant patients.

- Cyclosporine comes in 25 mg and 100 mg capsules, and liquid for oral use. It also comes as an (intravenous) IV preparation.
- The concentration of cyclosporine liquid is 100 mg/milliliter (ml). You will be told how many milliliters make up your child's cyclosporine dose. For example, 250 mg of cyclosporine = 2.5 mls. Know your dose and ask the nurse or pharmacist to show you how to find the dosage mark on the measuring device. It is important to take the correct amount of the drug.
- Blood levels of cyclosporine will be checked at least weekly to make sure that your child's dose is correct. The goal is to maintain a level that is effective without causing toxicities.
- Cyclosporine can damage kidney function. A high fluid intake helps to flush your child's kidneys and keep them functioning normally. The level of creatinine in the blood is a measure of kidney function. It increases if kidney function decreases.

**Fluid requirements increase while taking cyclosporine (your dietitian can provide this information):**

Goal: \_\_\_\_\_ cups/day (\_\_\_\_\_ ml/day)

**Cyclosporine causes magnesium loss from your body.** Your child will probably need to receive magnesium in IV fluid or TPN\*. As your child is able to eat and drink, his doctor will prescribe magnesium pills to be taken several times each day. Magnesium pills cause his bowel movements to become slightly loose or soft. If your child develop diarrhea, tell his doctor, nurse, or dietitian.

Most people taking cyclosporine cannot get enough magnesium from food alone; thus a supplement is still needed. Your child can get magnesium from these foods:

### **Excellent sources:**

Bran Cereals:  
All Bran®  
Bran Chex®  
100% Bran®  
Cracklin' Oat Bran®  
Most®

### **Good sources:**

Raisin Bran®  
Peanut butter  
Peanuts  
Whole wheat bread  
Quaker® Instant Oats  
40% Bran Flakes®

\*TPN is total parenteral nutrition, a form of nutritional support given intravenously, also called hyperalimentation.

### **Dose preparation**

1. Always wash your hands with warm, soapy water before and after preparing cyclosporine liquid doses.
2. Clean up any drops or spills to protect your family from getting the drug on their skin and to prevent oily stains on clothing or furniture.
3. Measure the cyclosporine liquid dose:
  - A measuring device is provided by the manufacturer. Follow the manufacturer's instructions for measuring the cyclosporine.
  - Squirt the cyclosporine into the desired diluting liquid. Stir well and drink at once. It is best to use a glass container and rinse it with more liquid to ensure the total dose is taken.
  - After use, dry the syringe with a clean paper towel or tissue and replace it in the clear case. To avoid cloudiness, do not rinse the syringe with water or other cleaning agents. If the syringe requires cleaning, it must be completely dry before using it again.

### **Cyclosporine blood levels**

On the day your child is to have blood levels measured, do not administer his morning cyclosporine dose until after the blood draw. Bring the cyclosporine with you to SCCA if you do not plan to return home after blood draw. Your child's nurse will inform you of his cyclosporine blood draw day.

### **Beverage and food recommendations**

Most people prefer to take the liquid format of cyclosporine with a flavored beverage such as chocolate milk, Ensure®, Boost®, Instant Breakfast® or Hawaiian Punch®.

Oral cyclosporine should **not** be taken with beverages containing the enzyme bergamottin such as grapefruit or grapefruit hybrids such as tangelos or honeybell oranges, Sunny Delight®, Fresca®, Squirt®, or Earl Grey tea. Please consult your dietitian, pharmacist, or nurse if you have questions about taking oral cyclosporine with other fruit juices or beverages.

It is good to eat breakfast or a small snack before taking the morning dose of oral cyclosporine. Some people find that taking cyclosporine by mouth on an empty stomach can result in nausea. If your child has eaten dinner within 2 to 3 hours, he may not need to eat again right before taking the evening cyclosporine dose. If cyclosporine continues to cause nausea, talk with your child's nurse, doctor, or dietitian.

### **Storage**

- Store cyclosporine, either liquid or capsules, at room temperature only. Do not store cyclosporine in the refrigerator or freezer or expose it to heat or strong light.
- Throw away partly used bottles of cyclosporine when two months have passed since opening.
- Keep your cyclosporine with you when you travel. Store the bottle in a plastic bag to protect purse, carry-on bag, or clothing.

### **Refills**

- Call the SCCA Pharmacy when your supply of cyclosporine gets low. Allow 24 hours for refills.
- Once you are discharged for home, cyclosporine will be prescribed by your local doctor. It can be obtained from your local pharmacy. Plan ahead with your doctor and pharmacist. Do not wait until you are completely out of medicine to get a refill.

### **IV cyclosporine**

- Rate: As prescribed. Cyclosporine can cause burning in hands and feet if it spills on your or your child's skin. If this occurs, call SCCA at (206) 606-7600 or the after-hours clinic at (206) 987-2032 (pediatrics).
- Cyclosporine must be infused in the white port only. **Do not infuse** in the blood draw side of your central line.

- Keep IV cyclosporine in the refrigerator.

## Tacrolimus

Tacrolimus is an immune-suppressing drug used to treat or prevent graft versus-host disease (GVHD) in bone marrow/stem cell transplant patients.

Tacrolimus comes in 0.5mg, 1mg, and 5mg capsules for oral use. It also comes as an IV preparation and a liquid form made by the pharmacy. The concentration of tacrolimus liquid is 1mg/milliliter (ml). You will be told how many milliliters make up your child's tacrolimus dose. For example, 1mg of Tacrolimus = 1ml. Know your child's dose and ask the nurse or pharmacist to show you how to find the dosage mark on the measuring device. It is important your child takes the correct amount of the drug. Blood levels of tacrolimus will be checked at least weekly to make sure that your child's dose is correct. The goal is to maintain a level that is effective without causing toxicities. Tacrolimus can damage kidney function. A high fluid intake helps to flush your child's kidneys and keep them functioning normally. The level of creatinine in your child's blood is a measure of kidney function. It increases if kidney function decreases.

### **Fluid requirements increase while taking tacrolimus (your dietitian can provide this information):**

Goal: \_\_\_\_\_ cups/day (\_\_\_\_\_ ml/day)

**Tacrolimus causes magnesium loss from your body.** Your child will probably need to receive magnesium in their intravenous fluids. As your child is able to eat and drink, your doctor will prescribe magnesium pills to be taken several times each day. Magnesium pills cause bowel movements to become slightly loose or soft. If your child develops diarrhea, tell your doctor, nurse or dietitian.

Most people taking tacrolimus cannot get enough magnesium from food alone; thus a supplement is still needed. Your child can get magnesium from these foods:

#### **Excellent sources:**

Bran Cereals:  
All Bran®  
Bran Chex®  
100% Bran®  
Cracklin' Oat Bran®  
Most®

#### **Good sources:**

Raisin Bran®  
Peanut butter  
Peanuts  
Whole wheat bread  
Quaker® Instant Oats  
40% Bran Flakes®

## **Dose preparation**

1. Always wash your hands with warm, soapy water before and after preparing tacrolimus liquid doses.
2. Clean up any drops or spills to protect your family from getting the drug on their skin and to prevent oily stains on clothing or furniture.
3. Measure the tacrolimus liquid dose:
  - A measuring device is provided by the manufacturer. Follow the manufacturer's instructions for measuring the cyclosporine.
  - Squirt the tacrolimus into the desired diluting liquid. Stir well and drink at once. It is best to use a glass container and rinse it with more liquid to ensure the total dose is taken.
  - After use, dry the syringe with a clean paper towel or tissue and replace it in the clear case. To avoid cloudiness, do not rinse the syringe with water or other cleaning agents. If the syringe requires cleaning, it must be completely dry before using it again.

### **Tacrolimus blood levels**

On the day your child has her blood levels measured, do not give her the morning dose of tacrolimus until *after* the blood draw. Bring the tacrolimus with you to SCCA if you do not plan to return home after blood draw.

### **Beverage and food recommendations**

Some people prefer to take the liquid form of tacrolimus with a flavored beverage such as chocolate milk, Ensure®, Boost®, Instant Breakfast® or Hawaiian Punch®.

Oral tacrolimus should **not** be taken with beverages containing enzyme bergamottin such as grapefruit or grapefruit hybrids such as tangelos or honeybell oranges, Sunny Delight®, Fresca®, Squirt®, Earl Grey tea. Please consult your child's dietitian, pharmacist, or nurse if you have questions about taking oral tacrolimus with other fruit juices or beverages.

### **It is good to eat breakfast or a small snack before your child takes her morning dose of oral tacrolimus.**

Some people find that taking tacrolimus by mouth on an empty stomach can result in nausea. If your child has eaten dinner within 2 to 3 hours, she may not need to eat again right before taking the evening tacrolimus dose. If tacrolimus continues to cause nausea, talk with your child's nurse, doctor, or dietitian.

### **Storage**

- Store tacrolimus liquid or capsules at room temperature only. Do not store tacrolimus in the refrigerator or freezer or expose it to heat or strong light.
- Keep your tacrolimus with you when you travel.
- Call the SCCA Pharmacy when your child's supply of tacrolimus gets low. Allow 24 hours for refills.
- Once your child is discharged for home, tacrolimus will be prescribed by your child's local doctor. It can be obtained from your local pharmacy. Plan ahead with your doctor and pharmacist. Do not wait until you child is completely out of medicine to get a refill.

### **IV tacrolimus**

- Rate: As prescribed. Tacrolimus can cause burning in hands and feet if it spills on your or your child's skin. If this occurs, call SCCA at (206) 606-7600 or the after-hours clinic at (206) 987-2032 (pediatrics).
- Tacrolimus must be infused in the white port only. **Do not infuse** in the blood draw side of your central line.
- Keep IV tacrolimus in the refrigerator.

## Prednisone

- Prednisone is an immune suppressing drug used to treat or prevent graft-versus-host disease (GVHD) in bone marrow and peripheral blood stem cell transplant patients.
- Prednisone comes in several sizes of tablets for oral use. It also comes as an IV preparation.
- Your child may need to use several different milligram sizes of tablets to take the prescribed total dose. You may also need to cut your child's pills in half to take the prescribed dose.
- Never take oral prednisone on an empty stomach. Give your child her morning dose of prednisone after breakfast or at least with a glass of milk, a serving of Ensure®, Boost®, or Scandishake®. If your child has eaten dinner within 2 to 3 hours, she does not need to eat again right before taking the evening dose.

### Nutrition recommendations during prednisone therapy

- **Consume a protein-rich diet while taking prednisone.** Your child may experience muscle loss while taking prednisone, even if her weight is stable or increasing. A protein-rich diet and regular exercise may help to maintain your child's muscles. Your child's dietitian will give you a protein goal.
- **Consume a calcium-rich diet while taking prednisone.** Calcium goal: 1500 mg daily. Prednisone can cause bone loss. Vitamin D and calcium, as well as exercise, can help minimize this loss. Your child's dietitian will assess her current calcium intake and recommend supplements if needed. Calcium carbonate (such as Tums®) or calcium citrate are recommended supplements.
- **Prednisone may increase blood glucose (sugar) level, similar to diabetes.** A normal fasting blood glucose level is 60 to 110 mg/dl. If your child's fasting blood glucose level is above normal, your dietitian may advise her to make some diet changes. She may be asked to avoid concentrated sweets.

Examples include:

|             |         |           |             |
|-------------|---------|-----------|-------------|
| Cake        | Cookies | Ice cream | Sugar       |
| Candy       | Donuts  | Muffins   | Sweet rolls |
| Coffee cake | Honey   | Pie       | Syrup       |

Levels of blood glucose usually return to normal when prednisone is stopped.

- **Your child may need more potassium in her diet while taking prednisone.** Prednisone causes some people to "waste" potassium into their urine. If your child's blood potassium level is below normal, her doctor may prescribe a potassium supplement. Potassium comes from these foods:

|                 |              |          |          |
|-----------------|--------------|----------|----------|
| Salt substitute | Bananas      | Melons   | Oranges  |
| Tomato juice    | Orange juice | Potatoes | Tomatoes |

Prednisone can cause your body to retain fluids. A high salt intake can worsen fluid retention. Avoid salt and salty foods such as canned, instant, and frozen soups and entrees; soy sauce; cured meats; and packaged sauces and seasonings. In general, processed foods contain excess salt. Your child's dietitian can provide you with more information about diet recommendations during prednisone therapy.

## **Mycophenolate mofetil (also called MMF or CellCept®)**

- MMF is an immune-suppression drug used to treat or prevent graft-versus-host-disease (GVHD) in stem cell transplant patients.
- MMF is available as a 250mg tablet, 500 mg capsule, liquid form, or IV infusion. Swallow the tablet and capsules whole; **do not break, crush, chew, or open the capsule or tablet**. Do not mix the liquid form with any other medicines.
- MMF can cause nausea, vomiting, constipation, abdominal cramps, diarrhea, muscle pain, headache, and/or swelling of the feet or lower legs. Your child's MMF dosing may be given every 8 or 12 hours.

### **MMF blood levels**

- Some patients may need to have MMF levels drawn. This would require several blood draws over an 8 to 10 hour period on these days.

### **Beverage and food recommendations**

- MMF is absorbed best on an empty stomach. If your child is having problems with nausea, have him take the medication with some crackers.
- Do not take within 2 hours of dairy, oral calcium, or oral magnesium supplements.

### **Storage**

- Keep tablets and capsules in a closed container at room temperature away from excessive heat, moisture, and direct sunlight.
- The oral liquid may be stored in the refrigerator but not in the freezer. The oral liquid expires 60 days from the time you receive it from the pharmacy. Dispose of any unused medication at that time.

Do not refrigerate intravenous infusions of MMF. It cannot be mixed with saline flushes. Lines need to be flushed with 50ml of dextrose 5% in water **before** and **after** the completion of each infusion. Discuss this with your child's nurse or pharmacist to make sure you understand this instruction.

## Sample transplant outpatient medication schedule

Bring this sheet to the first clinical visit. Include all medications. Indicate those given at home with an "H."

| Medication                                                                                  | Dosage/<br>directions                        | 6<br>a               | 7<br>a | 8<br>a | 9<br>a | 1<br>0 | 1<br>1 | 1<br>2 | 1<br>p | 2<br>p | 3<br>p | 4<br>p       | 5<br>p | 6<br>p | 7<br>p | 8<br>p | 9<br>p | 10<br>-<br>12<br>p |
|---------------------------------------------------------------------------------------------|----------------------------------------------|----------------------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------------|--------|--------|--------|--------|--------|--------------------|
| [ ] Bactrim:<br>[ ] Dapsone:<br>Discontinue Day -2:<br>_____                                | [ ] 1 DS tablet x 1/day<br>[ ] 50 mg x 1/day |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
| Acyclovir:<br>Begin Day -4:<br>_____                                                        | _____mg<br>x 2/day                           |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
| Fluconazole:<br>Begin Day -4:<br>_____                                                      | _____mg<br>x 1/day                           |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
| Multivitamin                                                                                | 1 tablet x 1/day                             |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
| Cyclosporine:<br>Begin Day -3:<br>_____                                                     | _____mg<br>x 2/day                           |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
| MMF (mycophenolate<br>mofetil):<br>Begin Day 0 (4 to 6 hours<br>after stem cells finished): | _____mg<br>x 2/day                           |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
| Kytril:<br>Take Day 0, ½ hour<br>before TBI:<br>_____<br>_____                              | 1 mg<br>_____<br>_____                       |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
|                                                                                             |                                              |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
|                                                                                             |                                              |                      |        |        |        |        |        |        |        |        |        |              |        |        |        |        |        |                    |
| Every 4 hours as needed:                                                                    | Ativan 0.5 to 2 mg                           | Benadryl 25 to 50 mg |        |        |        |        |        |        |        |        |        | Compazine 10 |        |        |        |        |        |                    |

### Suggested medication schedule

Bring this sheet to first clinical visit. Include all medications. Indicate those given at home with an "H."

[illegible]

## Chapter 4 – Long Term Recovery



**“The actual BMT in the hospital was doable, the recovery is the hard part.”  
-BMT survivor**



## How to take care of your child in the first year

“The most important advice I could ever give to someone dealing with life after transplant is: waste no time wishing you could get back exactly to where you were before transplant. Your life will instantly become more fulfilling and enjoyable the moment you stop being, say 70%, of what you used to be and becoming 100% of what you are now!”

-BMT Survivor

### What to expect moving forward?

The long-term recovery phase may take a year or longer. This is the time to reestablish your child's life after transplant. What does reestablishing your child's life entail? It means gradually getting back to you, your child's, and your family's life patterns at school or at home and making adjustments in relationships with your family and friends. It may also mean learning to adjust to the therapy needed for chronic or long-term complications. Former patients have noted that the interruption of life plans, the adjustment in relationships, and preparing to re-enter family life can be a difficult adjustment. Your child and other family members may experience a sense of loss or discouragement. Some people become involved in the quest for deeper meaning in their lives. Your family may want to seek therapy to help cope with chronic health issues and emotional responses to the challenges of treatment and recovery. Your child and family may find that everyone will benefit from counseling to gain tools for coping with issues of chronic illness, feelings of loss, anxiety, stress, worry, and depression.

Reestablishing life may vary from difficult and rough, to easy and smooth. During their recovery some patients express a positive view caused by achieving a redirected life, greater compassion for others and improved family relations. The majority of survivors report that their quality of life is now the same or better than before transplant. On the other hand, some patients struggle and become discouraged as they cope with the various life changes. Despite the intensity of the transplant experience, most patients make effective adjustments in their life and maintain an optimistic outlook for the future.

In addition to the information in this manual, you and your child will receive information from doctors and nurses that will help manage your child's care when you leave SCCA.

Take pride in your child's journey through an intensive medical treatment, but remember that full strength and fitness will take several more months, or sometimes years, to achieve. Recovery is usually a gradual process. Remember rest, exercise, and good nutrition are the cornerstone to recovery.

### Transition to home

The Long-Term Follow- Up (LTFU) department offers telephone consultation services to you and your child's primary doctor when you return home. Call your local doctor for everyday concerns. Call your SCCA care team for treatment-related issues. LTFU consultation is available at SCCA if you or your child's doctor are concerned about transplant-related side effects or complications. It is a real possibility that your child may be readmitted to a hospital during her first year after transplant.

## Self-care steps

You can play a proactive role in your child's recovery by taking responsibility for the following self-care steps.

### Doctor's visits

These include physical exams, as well as labs and tests (such as blood counts and kidney and liver function tests). Our standard recommendations are:

- Weekly visits for the first month and every other week for the next 2 months. Then go once every 3 to 4 weeks, depending on your child's progress. Your doctor will help you decide.
- A one year follow-up evaluation is necessary to assess disease status, late complications and to receive vaccinations. Call (206) 667-4415 to make your child's one year follow-up appointment.

### Skin care

Note any of the following changes in skin, and report them to your doctor:

- Color changes
- Rash
- Lesions
- Scaly skin
- Texture changes and thickening
- Stiff or tight skin around joints

It is important to protect your child from UVA and UVB (ultraviolet A and B) radiation from sun exposure for two reasons: exposure can cause sun-activated, chronic graft-versus-host disease (GVHD) of the skin and add to the increased risk of skin cancer. Take the following steps to protect your child from harmful rays. These are smart sun care steps for everyone for everyone to take, not just patients.

- Use sunscreen: SPF 30 or greater is recommended for everyone, reapply every hour while outdoors.
- Protect your child's lips with SPF 30 (sun protection factor) lip balm.
- Wear clothing with SPF protectant manufactured into the fabric such as Columbia®, Solumbra®, and ExOfficio®.
- Avoid long (over 1 hour) exposure to sun.
- Apply sunblock or wear SPF clothing even on cloudy days, as they still result in exposure to ultraviolet radiation.

If dry skin is a problem, it is not necessary to bathe daily.

- Use oil in bath water
- Use lotion
- Try natural soap for sensitive skin

### Nail care

**Your child should not have manicure and pedicures if her immune system is still recovering and on antibiotics.** Avoid fake nails and cutting the cuticles. If your child's ANC (absolute neutrophil count) is greater than 1,500 without need for transfusions, and she is off high dose steroids (greater than 1mg/kg), she can have a manicure or pedicure. Make sure a single basin is used, and equipment is sterilized after each person. Check the facility's license: <https://fortress.wa.gov/dol/dolprod/bpdLicenseQuery/> Choose "Cosmetologist, Barber, Manicurist, Esthetician".

## **Eye care**

Visit your child's eye doctor (optometrist or ophthalmologist) for any of the following changes:

- "Gritty" feeling
- Discharge
- Changes in vision
- Continual redness
- Continual dryness without relief from eye drops
- Pain or sensitivity to light
- Sensitivity to wind
- Burning
- Excessive tears

Of the patients who receive total body irradiation before their transplant, 20% develop cataracts within 1 to 5 years after transplantation. Cataracts are also more common in patients who receive long-term steroids. Cataracts can be removed surgically and the lenses will be replaced. Many patients who develop chronic GVHD will experience eye problems, which can be severe. Adequate management of GVHD of the eyes is necessary to avoid severe complications (see chronic GVHD section). Discuss with your eye doctor whether it is appropriate to change the prescription for your child's glasses. You may wait until your child is receiving less medication such as prednisone that can affect eyesight.

## **Daily mouth care**

Careful flossing and brushing are important to maintain dental health and prevent infections. Continued use of saline rinses can help if your child's mouth is dry, if your child has excessive mucous, or if your child is being treated for oral fungus. Your child can rinse her mouth using  $\frac{3}{4}$  teaspoon table salt in 1 quart of warm water.

## **Dental visits**

See a dentist six months after returning home for an exam to monitor tooth decay and overall oral care. Routine dental cleaning and dental work should be postponed for at least 12 months after transplant, longer if your child is still on an immunosuppressant. Your child's dentist should also monitor for oral cancer every 6 months. If dental work is necessary and your child is still receiving immunosuppressant medication, he will need an antibiotic based on recommendations from the American Heart Association. If urgent dental care is needed in the first year or while your child is still on drugs that affect his immune system (those that help prevent or treat graft-versus-host disease), he should take oral antibiotics prescribed by his doctor, before dental work is done.

## **Dry mouth**

See a dentist if your child has extreme problems with decay. However, fluoride and excellent oral hygiene can minimize or prevent this. Daily home use of fluoride brush-on gels or custom fluoride trays is recommended. Follow guidelines provided by SCCA Oral Medicine department. Saline rinses or other non-prescription products, such as Biotene®, can help to relieve dryness.

## **Mouth changes**

Contact your child's doctor for any changes such as ulcers, mucoceles (clear blisters on the soft area of the roof of your mouth or the inside of your lower lip), stinging, burning, dryness, pain, difficulty eating or swallowing, or loose adult teeth.

## Common changes

**“The new normal is not a bad normal, just different. Perspective is everything.”**

**-BMT Survivor**

### Cognitive

The issue of cognitive changes is receiving more research attention. Cancer causes biochemical changes that are now suspected of contributing to cognitive changes, even before any treatment. High-dose chemotherapy and radiation affect cognitive function. Studies show varying incidences of “chemo brain” among transplant patients. However, research indicates that post-treatment cognitive changes, which are characterized by a decrease in memory, multi-tasking ability, and attention resolve for most people after about a year. Patients can return to their pre-transplant cognitive functioning anywhere from one to five years post-transplant. Some people will continue to have memory or fine motor difficulties. If your child is still having difficulties with cognitive changes after one year, ask her doctor for a referral for neuropsychological testing so you know what your child’s deficits are and what you can do about them. In the meantime, help your child’s memory by encouraging them to keep a notebook of things they want to remember. They can also make sticky notes about what they do not want to forget, like taking a medication before they go to bed. Put the sticky note by something your child always remembers, like brushing teeth. Keep a basket by the door for the things your child needs to take with him, like glasses.

### Sleep

Most people have difficulty with sleep at some point during and after transplant. It can be hard to get on a regular cycle of sleep and worry tends to increase as people lie in bed awake. Medication should be a short term solution, not a lifetime aid. Tips that help to promote sleep include keeping the bedroom dark and cool and going to bed and getting up at the same time each day. It may be helpful for your child to get out of bed and do a relaxing activity like reading if she does not sleep after 30 minutes of trying. Your child can also learn relaxation skills to help body and mind to relax while lying in bed.

### Depression and other feelings

**“People are entitled to their feelings. And they’re entitled to them at every stage of treatment and survivorship. We know from the science of emotion that the most harmful way, the most damaging way, to manage emotions is to try to dictate them.”**

**-Dr. Karen Syrjala (in Surviving Survivor Stereotypes by Curtis Pesmen)**

Your child may continue to experience significant distress following transplant. Sometimes, this can lead to feelings of sadness or depression and associated symptoms such as worry, anger, and fatigue. Distress can also lead to changes in sleep and eating patterns. Even post-traumatic stress can happen. We recommend making time and saving energy to participate in activities that your child enjoys, so life is not entirely about health. Spend time with friends and family. If these symptoms continue for more than a couple of weeks, it is important to discuss them with your child’s care team. Some people find that talking to a therapist after transplant is very helpful. There is so much that most people have been through and have to cope with after treatment. Talking with a therapist can help your child reclaim his life and make sense of what he has gone through.

## **Fatigue, weight, and exercise**

“Some problems such as fatigue can begin during therapy and may continue indefinitely, though the duration and severity differs greatly between individuals.”

-Rabiya Tuma, PhD, Treatment Aftershocks

Many people report increased fatigue after transplant. Exercise is an effective way to decrease this fatigue over time. We recommend a program of daily moderate exercise for your child, such as walking. Increase the distance and pace as your child's strength and stamina increase. It is also important to rebuild muscle through a program of gradually increasing weight training. Couple this with stretching, yoga, and gentle fitness classes. See if a YMCA or local gym near you has a low-cost cancer survivorship program or ask for a physical therapy referral to get an exercise plan from someone who has experience with exercise after cancer treatment. If your child exercises at a moderate level and has rebuilt muscle, but his fatigue continues or increases, talk to your child's doctor about other possible causes of fatigue. The best exercise is the one that your child does regularly! Follow recommendations for healthy eating from your child's dietitian.

## **Osteoporosis for allogeneic transplant patients**

Osteoporosis or bone loss may happen in some patients. It is related to irradiation, use of steroids, inactivity, and low hormone levels. Weight bearing exercise is recommended to help prevent or stabilize osteoporosis. Your child may need calcium and vitamin D supplements or bone rebuilding medications. You can discuss this with your child's dietitian.

## **Immune system recovery**

Adequate immune function takes approximately one year after transplantation to recover. Adequate immune function may take longer if your child has chronic GVHD or is taking medications that suppress her immune system. During this time your child is still vulnerable to infections. Symptoms such as fever, chills, coughing, difficulty breathing, severe diarrhea, or vomiting should be promptly reported to your doctor.

### **Cytomegalovirus (CMV) monitoring**

Your child may need weekly CMV monitoring after treatment. At discharge from SCCA, you will receive specific recommendations to take to your child's local doctor.

### **Exposure to others**

Avoid crowds, especially during cold and flu season. Avoid people with a contagious infection. Please contact your doctor if your child is exposed to chicken pox or shingles.

### **Hand washing**

Continue to be as careful about hand washing as you have been throughout the transplant process. You, your child, and your family should perform hand hygiene frequently by washing hands with soap and water or applying an alcohol-based hand sanitizer that contains 60 to 85% alcohol. Ask family and friends to wash their hands or use hand sanitizer when they come into your home. Have your child wear disposable gloves if he must change a diaper. Wash hands after disposing of gloves.

### **Temperature**

Take your child's temperature if she is feeling ill, has shaking chills, or you suspect that she has a fever. Note time and circumstances. Notify your doctor promptly if your child has a:

- Temperature taken by mouth between 38 to 38.2°C (100.4 to 100.8°F) for one hour or more, or a temperature that is 38.3°C (100.9°F) or above.
- Temperature taken under the arm between 37.5 to 37.7°C (99.5 to 99.9°F) for one hour or more, or a temperature that is 37.8°C (100°F) or above.

### **Rash**

Notify your doctor promptly if any rash develops.

### **Animals and plants**

Avoid contact with body excretions of all animals and do not sleep with pets. Do not bring new pets into the home during the first year or thereafter, if your child is taking immunosuppressant medications. Established household pets and plants may remain in the home. Gardening is not recommended while on drugs that suppresses the immune system.

### **Sexual activity**

Limiting the number of sexual partners is advised. Condoms should be used for protection against sexually transmitted infections (STIs). Normal cleanliness should be observed. Birth control should be used as necessary to prevent pregnancy, as your child may not be sterile. Discuss with your child's doctor and nurse. If vaginal dryness is a problem, a lubricant may be helpful. Drugs used for impotence should be avoided while your child is on an immunosuppressant and should not be used without a cardiac evaluation.

## Swimming

Swimming may expose your child to germs capable of causing infections. You should measure the benefits of your child swimming against the potential risks of these infections. If swimming or water aerobics is the preferred or recommended method of exercise, it should be done in a well-maintained pool with adequate chlorination. Your child's face should not be submerged under the water. Never swim with a central line in place. Also, do not swim for the first 6 months after the transplant or if on drugs that treat GVHD within the first year. Hot tubs should not be used for the first 6 months after transplant or if your child is on drugs that treat GVHD.

## Travel

Take extra medications with you when you travel and consider where your child could receive the treatment he needs if he became ill. Move around during flight or transit time to prevent blood clots that could lead to a major lung problem.

Many patients travel home within the first 6 months after transplant. As with any activity involving risk, weigh the specifics of your situation. To minimize risks when traveling:

- Take a copy of your child's critical medical records with you.
- Seek medical care promptly for new symptoms.
- Control your environment by avoiding crowds and maintaining infection precautions.
- If you fly, ask to be moved if you are seated near someone with respiratory symptoms. Carry hand sanitizer and wipes.

## Other reminders

- **Minimize** exposure to dirt and aerosolized material.
- **Minimize** sun exposure, use sunscreen (SPF 30 or greater).
- **Use** a hat, long-sleeve shirts and long pants if outside for long period of time.
- **Avoid** construction sites.
- **Avoid** contact with people that:
  - Have cold and flu symptoms like coughing and sneezing.
  - Display symptoms of other types of infections such as vomiting or skin rashes.

# Immunizations

Patients generally receive post-transplant immunizations starting at one year. These killed-virus and killed-bacterial immunizations include:

- Tetanus
- Diphtheria
- Pertussis
- Meningococcal
- Inactivated polio
- Influenza
- Pneumonia
- Haemophilus influenza type B
- Hepatitis B
- Hepatitis A
- Human papilloma virus (HPV) (ages 9 to 26)

If you do not return for your child's one-year follow up, ask your doctor to contact the Long-Term Follow-Up department about immunizations. If a household member receives the Varicella (chickenpox) vaccine, your child should be taking acyclovir. If a household member develops lesions (or pox), your child needs to be isolated while their lesions are present.

## Graft-versus-host disease (GVHD)

One form of GVHD that may occur around day 80 or later is called chronic graft-versus-host disease. Approximately 50% of patients who receive allogeneic transplants are diagnosed with chronic GVHD, with variation in the incidence related to characteristics of the donor and the source of the stem cells. GVHD can affect any organ. Unfortunately, 15% of the patients develop severe chronic GVHD that goes on for many years and may lead to disability. The range of medical issues caused by GVHD can be mild to severe.

You might notice your child's skin becoming dry, scaly, and discolored with patches of thickened or hardened underlying tissue. The surface of the eyes and mouth can become dry. Mouth lesions may develop. Sometimes the esophagus, gastrointestinal tract, or liver are affected. Weight loss due to poor absorption of food or GVHD increased catabolism (burning more calories despite adequate eating) can occur. Bacterial infections are common. Treatment protocols have been developed for GVHD and the Long-Term Follow-Up team is available to your child and your child's doctor if she develops symptoms after going home. There may be some positive aspects to having GVHD. Patients with GVHD have a lower risk of the cancer returning after transplantation than patients who do not develop GVHD.

Report any of the following changes to your doctor. Make sure your doctor is watching for possible changes in your liver and kidney function test results as well.

- **Skin:** Rash, thickness, discoloration, tightness, texture changes, shining, itching
- **Hair:** Thinning or coarse
- **Nails:** Texture changes, brittleness, ridges
- **Eyes:** Dryness, grittiness, irritation, burning, blurring, discharge, tears, sensitivity to light or wind
- **Mouth:** Dryness, pain, sensitivity to hot/cold foods or toothpaste, ulcers, white lacy changes on gums and cheeks
- **Vagina:** Dryness, irritation, tightening
- **Penis:** Irritation
- **Digestive System:** Nausea, vomiting, diarrhea, loss of appetite, unexplained weight loss
- **Lungs:** Chronic dry cough, wheezing, shortness of breath
- **Liver:** Jaundice and elevated liver test numbers
- **Joints:** Unable to fully extend fingers, wrists, elbows, ankles or knees, joint pain, or stiffness
- **Energy Level:** Increased fatigue
- **Temperature sensitivity:** Cold intolerance, inability to sweat

### Treatment of GVHD

The duration for treatment of chronic GVHD with immunosuppressants (therapies that suppress the immune system such as prednisone, tacrolimus, cyclosporine, sirolimus, mycophenolate mofetil, and others) varies between 2 to 3 years after the initial diagnosis of this complication. Approximately 10% of patients require chronic GVHD treatment for seven years or longer. Eventually the graft will develop tolerance to the new body, and the GVHD will resolve without the need of treatment.

Therapies most commonly used for chronic GVHD are prednisone, cyclosporine, tacrolimus, rapamycin, mycophenolate mofetil, and others. All immunosuppressive drugs have some side effects. The most common toxicities of these drugs are listed below.

- **Prednisone:** Osteoporosis, deterioration of joints that can require joint replacement, increased risk of infections, diabetes, cataracts, and emotional changes, differences in body shape (weight gain, facial swelling or “moon face”)
- **Cyclosporine:** Kidney function issues, loss of magnesium, tremors, headaches, seizures, nausea, increased blood pressure
- **Tacrolimus (Prograf®):** Similar to cyclosporine
- **Mycophenolate mofetil (MMF or CellCept®):** Nausea, vomiting, diarrhea, bleeding, decreasing white blood cells count, anemia
- **Rapamycin, Sirolimus (Rapamune®):** Decreased white cells or platelets, increased triglyceride level, edema (fluid buildup that causes swelling), and others.

Despite the side effects of medications used to treat chronic GVHD, adherence to the treatment schedules and doses is of the utmost importance in the long term. Damage from untreated or undertreated chronic GVHD to the eyes, lungs, and skin cannot be reversed. This damage is worse than the side effects of the medications used to treat GVHD.

## Medications

Your child's medications are important to help her maintain general health. Please give them as prescribed.

- **Bactrim® (sulfamethoxazole-trimethoprim):** This is a broad spectrum antibiotic specifically for the prevention of pneumocystis pneumonia and for prevention of certain types of bacterial infections (Streptococcus pneumonia and Haemophilus influenza).
  - Take this medication if prescribed for at least 6 months after transplant, or longer if continued on immune suppression medications.
  - **Always take Bactrim® (or an alternate drug) when taking immune suppression medications.**
  - **If on tapering doses of immune suppression medications,** take Bactrim® until 6 months after treatment of chronic GVHD.
- **Acyclovir or valacyclovir:** These drugs are antiviral agents used to prevent varicella zoster (shingles). If one of these is prescribed, it should be taken for the entire first year, and should be given concurrently while on immunosuppression and for 6 months after completion of taper.
- **Hormones:** Hormones may be prescribed for women in premature menopause due to the effects of conditioning therapy.
- **Immunosuppression:** Keep accurate records of dates when stopping or restarting immunosuppressive medications (prednisone, cyclosporine, MMF, tacrolimus, rapamycin). Immunosuppressive medications may require that blood levels be checked.

## Secondary cancers

There is an increased risk of getting a different cancer in long term survivors after transplantation. The risk starts to increase at five years after transplantation. Skin, mouth, thyroid, and breast cancers are the most common sites of secondary cancers after transplant. Cancer screening evaluation is recommended and includes: complete skin examination, oral exams, breast exam and mammograms (women), prostate exam (men), colonoscopy (according to age and history), and others as needed. Original disease restaging is also recommended at periodic intervals depending on diagnosis. For patients transplanted for CML or acute lymphocytic leukemia PH+, blood monitoring for the BCR/ABL by PCR test is recommended periodically.

## Reconnecting with life and survivorship

“This has been five years that I wouldn’t wish on my worst enemy, but strangely enough, wouldn’t trade for the world.”

-BMT Survivor

It is normal to feel vulnerable after returning home. These feelings are valid, but don’t push the panic button every time someone sneezes! It’s important to see friends and return to normal activities. Just use common sense - “when in doubt, don’t.” Some patients, especially those who had a stormy transplant course, find it hard to plan for the future. Make a specific detailed plan for something your child wants to do. This helps your child to feel like he is moving toward something, not just marking time while he recovers.

### Helpful hints for your child to remember

- It is healthy to find a “silver lining” in your situation. It doesn’t mean that you forget the clouds, it’s just that the clouds are not the whole story.
- You are your own best friend. Take care of yourself. Get enough rest, exercise, and good nutrition. Be patient with yourself and others.
- Watch for changes in your body, hair, nails, eyes, skin, mouth, and joints. Tell your doctor of any changes.
- Try to take one day at a time; focus on your goals for today, particularly after you first return home. Make sure you include something you enjoy in each day.
- It is normal to feel alone at times; it’s true that no one else has been down your road and really knows what it is like for you. Make it a goal to connect with people and do activities you enjoy so that you start to feel like part of your community, even if at first you don’t feel like it.
- Remember that your caregiver and family have also been through a major challenge. Check in with them weekly to let each person describe what they are experiencing. You don’t need to fix each other’s concerns; just use this as a time to listen and reflect upon what each person is feeling. Ask if there is anything that would make things better.
- Do not be afraid to ask for professional guidance; you deserve it! Almost everyone receives some kind of help.
- SCCA suggests that you return one year following transplant for re-evaluation.

### Relationships

It may be difficult to resume relationships as they were before transplant because your child’s experience has changed her perspectives. Your child’s illness may have affected the feelings and perspectives of the people around him. It may have produced role changes that can affect relationships. People report that these changes can be very positive, but they also can take some time to sort out. Make sure each person in your family has a chance to describe their fears and concerns. Even if it is hard, try to give each person time to describe what is going on in their lives and thoughts. As a caregiver, you may be used to taking care of your child and home tasks. These role changes can take time to get back to normal. It can be helpful to discuss a weekly plan of who will do what. As your child is ready for more responsibility, help her communicate this to her caregivers. With your child’s friends, it might help to discuss what is different in his life and how much the friendship means to him. Sometimes your child may have to reach out to friends rather than waiting for them to come to him.

## Returning to work or school

Returning to work or school is very complicated. You and your child need to be ready both physically and emotionally. We suggest that you wait 6 to 12 months after transplant to return to work or school, but home tutoring or work in a home office can precede these dates. If your child has contributed to Social Security, he or she may be eligible for social security benefits because of their inadequate immune system. This will be the case for at least one year and possibly longer if your child is on immunosuppressive medication for GVHD. There are many organizations that assist cancer and transplant survivors with employment issues. For more information on your child's employment rights, see the Resources section at the end of this chapter.

The Department of Vocational Rehabilitation offers counseling to for emotional or physical disabilities. Some people are eligible for Social Security. See below for additional information:

- Department of Vocational Rehabilitation [www.dshs.wa.gov/dvr/](http://www.dshs.wa.gov/dvr/)
- Americans with Disability Act [www.ada.gov/](http://www.ada.gov/)
- Cancer and Careers [www.cancerandcareers.org](http://www.cancerandcareers.org)

## Financial concerns

Many people report insurance and financial concerns. We recommend that you look into Social Security and private disability insurance. Look online and at the resources at the end of this chapter for more information on cancer and financial concerns.

## Young adults

The road to independence and maturity is more difficult for young adults who have been ill. Feelings may fluctuate, sometimes viewing parents as being overly concerned and involved, and at other times feeling insecure and wanting more parental guidance and reassurance. Many young adults report that starting to date and sexual activity can bring uncertainty. An excellent resource for young adults experiencing this is <https://www.livestrong.org/we-can-help/young-adults>.

## Sexuality

"Nobody wants to talk about it. It becomes a self-propelling problem, in that, the longer time goes by, people then also become kind of less connected with that part of themselves."

-Sharon Bober, PhD

Most people notice a drop in sexual desire during the first year. Young adults can make time for intimacy to re-awaken those feelings. They may have a low energy level or feel unattractive due to the changes that their body has undergone. Partners often hesitate to make sexual advances out of concern for a patient's health. Young women can have vaginal changes and young men may have erection problems. Medications can be the cause of some of these changes; problems may disappear over time or after stopping the drugs. Hormones can change for young men and young women after transplant. For young men, it often takes a full year for testosterone levels to return to normal, affecting both erections and desire. It's important for both partners to talk about their feelings and to be patient with one another. Begin to set aside "date" time to be romantic, include touching during intimate time together. Young adults can start trying sexual activity even if desire is not back to its previous level. If dryness or irritation is a problem, a silicone-based lubricant can be helpful. Water-based lubricants are also safe, but won't last as long. If graft-versus-host disease or sensitivity is a problem, ask to see a sexuality-after-cancer specialist or look online at BMT websites on sexuality to learn more about what can be done for these problems. After cardiac evaluation, drugs used for erectile problems can be helpful for some men.

## Survivor syndrome

“Little studied, survivor guilt brings with it a host of issues that can cause depression, anger, and self-blame that may even compromise health.”

-Kathy Latour, Getting Through Survivor Guilt

Your child may have feelings of guilt because she is alive when others did not survive. Your child may also have a strong sense of grief and loss. Even though your child is glad to be alive, it is normal to feel that she has lost things that she will never again be able to regain. Discussion with a counselor, minister, priest, or rabbi can help put this in perspective. If your child isn't sure what she wants to do, or feels like she wants a change, give her time to recover while she discovers what she wants most. Some people re-evaluate what they want to do for the rest of their life. Having survived this adventure, your child might decide to try another new one!

## Survivorship Clinic

Cancer and its treatment can result in some potentially long-lasting or late-onset effects. The SCCA Survivorship Clinic addresses various problems cancer survivors may face after therapy ends. These include pain, fatigue, and fear of recurrence, living with uncertainty, neuropathy, lymphedema, bone loss, sexual dysfunction, cardiovascular disease, memory issues, and future cancer risk. At the Survivorship Clinic, our medical staff will talk with you and your child about how to assess and manage late complications or issues your child may be experiencing and develop a plan to support your child's future health.

As part of your child's appointment in the Survivorship Clinic you will receive an individualized [Treatment Summary and Survivorship Care Plan](#). This includes an evaluation and information on the prevention of the late effects of your cancer and cancer treatment, recommendations and resources for dealing with long-term effects, and suggestions for healthy lifestyle behaviors. Copies of the treatment summary, survivorship care plan, and any recommendations made during the appointment are shared with your child's healthcare team, including the SCCA physician and primary care (local) physician. We will work in partnership with these doctors to make sure your child's survivorship needs are being met. We do not provide testing for recurrence of your child's cancer; this care will continue to be provided by your SCCA care team. To schedule an appointment in the SCCA Survivorship Clinic please call (206) 606-1024. Visit the Survivorship Clinic website at: [www.fredhutch.org/en/treatment/survivorship/survivorship-clinic.html](http://www.fredhutch.org/en/treatment/survivorship/survivorship-clinic.html)

Transitional Transplant Clinic (TTC) is a clinic for patients with complex conditions such as GVHD that is not well controlled, serious infections, or other complex conditions that require extensive ongoing management. Talk with your child's nurse if this is right for you and your child.

# Sample letter for returning home

To my family and friends:

I am recovering from a bone marrow transplant. I am able to return home; however, my recovery from this procedure can take months. The following is a list of some of the ways you can help with my recovery.

## **My risk for infection continues**

It will take at least \_\_\_\_ months for my immune system to recover. It's possible that it could take even longer, depending on what medications I will need or what complications I might experience. I am at a higher risk for infection and will need to pick activities that will minimize my risk of infection. Family and friends need to be up to date with their vaccinations. Please see the vaccination recommendations in the Preparing for Transplant booklet.

## **Hand washing etiquette**

Hand washing is the most effective way to prevent infection from spreading. I was taught to wash my hands frequently. My family, friends and visitors will be asked to do the same when in my company. Please don't be offended if I remind you to wash your hands.

## **Time to eat**

I have to follow a special diet while my immune system recovers. If you wish to help by providing meals, I would be happy to give you a list of what I can and cannot eat.

## **Fatigue**

I will have good days and bad days. I would like to see you; however, short visits will be better for me. Some days I might not be up to visitors, long conversations or involved activities. Exercise can help with fatigue so please offer to walk with me.

## **Memory and concentration**

The treatment and medications I take can affect my memory and ability to concentrate.

## **My caregiver**

\_\_\_\_\_ had a lot of responsibility while we were in Seattle. Now that we are home, \_\_\_\_\_ will still have caregiver responsibilities along with all the usual home and work routines. If you would like to help, please see the list of suggestions below:

- Drive me to and from appointments.
- Run errands for my caregiver or visit with me so my caregiver can have a break.
- Take my children out for an activity.
- Help with household chores and/or yard work.
- Remember my caregiver with a phone call or offer to do something fun.
- Join me for a walk!
- Walk the dog.

And please remember, all of your help and phone calls are appreciated as I move forward with my "post-transplant" life! The support of family and friends is an integral part of this transition. Thank you so much for your support.

Sincerely,

# Survivorship Resources and Websites

## Post-transplant networks

Blood and Marrow Transplant Information Network

[www.bmtinfonet.org](http://www.bmtinfonet.org)

Be the Match

[www.bethematch.org](http://www.bethematch.org)

Bone Marrow Transplant Forum, BMT-TALK: To subscribe to the mailing list, send an email with “Subscribe BMT-TALK” in the message body along with your first and last name to: [listserv@listserv.acor.org](mailto:listserv@listserv.acor.org)

Patients Cancer Survivors Network: emotional support for transplant

<https://www.csn.cancer.org/>

## Recommended tests and procedures

Center for International Blood & Marrow Transplant Research

[www.cibmtr.org](http://www.cibmtr.org)

## Fertility

Resolve support group for infertile couples:

[www.resolve.org](http://www.resolve.org)

## Help with post-transplant medication costs

Patient Access Network Foundation

[www.panfoundation.org](http://www.panfoundation.org)

## Hospitals and clinics

Seattle Cancer Care Alliance

[www.seattlecca.org](http://www.seattlecca.org)

Fred Hutch

[www.fredhutch.org](http://www.fredhutch.org)

University of Washington Medical Center

[www.uwmedicine.org](http://www.uwmedicine.org)

Seattle Children’s

[www.seattlechildrens.org](http://www.seattlechildrens.org)

## Insurance and employment rights

Cancer Advocacy Now

[www.canceradvocacy.org/cancer-advocacy-now](http://www.canceradvocacy.org/cancer-advocacy-now)

Employment Rights Cancer and the Americans with Disabilities Act

[www.eeoc.gov/facts/cancer.html](http://www.eeoc.gov/facts/cancer.html)

The Job Accommodation Network

[www.askjan.org](http://www.askjan.org)

Fair Employment for Cancer Patients and Survivors

[www.canceradvocacy.org/resources/employment-rights/how-employment-discrimination-laws-protect-cancer-survivors](http://www.canceradvocacy.org/resources/employment-rights/how-employment-discrimination-laws-protect-cancer-survivors)

American Cancer Society

Health Insurance

[www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html)

## **National Organizations**

National Bone Marrow Transplant Link

[www.nbmtlink.org](http://www.nbmtlink.org)

National Cancer Institute

Search “Facing Forward: Life After Cancer”

[www.cancer.gov](http://www.cancer.gov)

National Marrow Donor Program

Search “Post-Transplant Care”

[www.bethematchclinical.org/post-transplant-care](http://www.bethematchclinical.org/post-transplant-care)

National LGBT Cancer Network

[www.cancer-network.org](http://www.cancer-network.org)

American Cancer Society

[www.cancer.org](http://www.cancer.org)

National Coalition for Cancer Survivorship

[www.canceradvocacy.org](http://www.canceradvocacy.org)

## **Men’s Health**

Men’s Health Network

[www.menshealthnetwork.org](http://www.menshealthnetwork.org)

## **Pediatric**

American Childhood Cancer Organization

[www.acco.org](http://www.acco.org)

Children’s Oncology Group

[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

Human Growth Foundation

[www.hgfound.org/](http://www.hgfound.org/)

## **Skin care**

Skin Cancer

[www.skincancer.org](http://www.skincancer.org)

Sun Safety

Search “Sun Safety”

[www.fda.gov](http://www.fda.gov)

Sun Precautions Clothing

[www.sunprecautions.com](http://www.sunprecautions.com) or phone number 1-800-882-7860

## **Women’s health**

North American Menopause Society

[www.menopause.org](http://www.menopause.org)

National Women’s Health Network

[www.nwhn.org](http://www.nwhn.org)

## **Young Adult**

Livestrong

[www.livestrong.org/we-can-help/young-adults](http://www.livestrong.org/we-can-help/young-adults)

## **The Long-Term Follow-Up Department**

Please contact your local physician for medical needs or emergencies. If you have transplant-related questions that your physician can not answer, or you need to schedule your long-term follow-up appointment, leave a voice mail message and a staff member will return your call. Please leave the spelling of your name in addition to your question. We will attempt to return your call within 24 to 48 hours during weekdays. Your message will be reviewed and an experienced transplant nurse will return your call within 24 to 48 hours.

Contact Information for LTFU

Phone number: (206) 667-4415

Toll-Free Fax: (206) 376-8197

Local Fax: (206) 667-5619

Email: [LTFU@seattlecca.org](mailto:LTFU@seattlecca.org)

### **Fred Hutch Long-Term Follow-Up:**

[www.fredhutch.org/en/treatment/long-term-follow-up.html](http://www.fredhutch.org/en/treatment/long-term-follow-up.html)

Click on “Information for Patients” in the left-hand navigation column.

### **Long-Term Follow-Up physician program guidelines:**

[www.fredhutch.org/en/treatment/long-term-follow-up/information-for-physicians.html](http://www.fredhutch.org/en/treatment/long-term-follow-up/information-for-physicians.html)

## Common infection control questions

| Questions often asked                                                                                                                                                                                                                                                                                                                                       | Time after transplant        |                                  |                              |                              |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|----------------------------------|------------------------------|------------------------------|
| The general guidelines below may not apply to your case. You must discuss these rules with your physician to assess if they apply to you. See key at the bottom of the table for numbered footnotes.<br><b>Pediatric patients:</b> Discuss with your physician when restrictions may continue to apply to your child's care after one-year post-transplant. | All patients post-transplant | Not receiving immuno-suppression | Receiving immuno-suppression | Receiving immuno-suppression |
|                                                                                                                                                                                                                                                                                                                                                             | From 3 to 6 months           | From 6 months to 1 year          | 6 months to 1 year           | More than 1 year             |
| <b>Animals, birds, reptiles, fish</b>                                                                                                                                                                                                                                                                                                                       |                              |                                  |                              |                              |
| Small cage rodents (gerbils, rabbits, hamsters, guinea pigs, hedgehogs, prairie dogs, ferrets, others)<br><b>Do not handle</b>                                                                                                                                                                                                                              | No                           | Ok                               | Ok                           | Ok                           |
| Reptiles and amphibians (snakes, turtles, frogs, lizards, and iguanas) <b>Do not handle</b>                                                                                                                                                                                                                                                                 | No                           | No                               | No                           | No                           |
| Farm animals (pigs, horses, cows, llamas, others)<br><b>Do not handle; stay out of barns full of hay</b>                                                                                                                                                                                                                                                    | No                           | Ok                               | Ok                           | Ok                           |
| Exotic, wild, and game animals (deer, elk, squirrels, bear, and monkeys)<br><b>Do not handle</b>                                                                                                                                                                                                                                                            | No                           | No                               | No                           | No                           |
| Zoos and petting zoos                                                                                                                                                                                                                                                                                                                                       | No                           | No                               | No                           | No                           |
| Aquariums (3)<br><b>Do not touch marine life in handling tanks</b>                                                                                                                                                                                                                                                                                          | No                           | Ok (3)                           | Ok (3)                       | Ok (3)                       |
| Animal trophy mounts in the house                                                                                                                                                                                                                                                                                                                           | Ok                           | Ok                               | Ok                           | Ok                           |
| Fishing (fresh and salt water)<br>OK to handle fish if wearing gloves; <b>do not bait hooks</b>                                                                                                                                                                                                                                                             | Ok                           | Ok                               | Ok                           | Ok                           |
| Hunting (wild game and birds) and sport shooting (2) (Wear latex gloves when handling game; do not clean game with a venous catheter device)                                                                                                                                                                                                                | No                           | Ok (2)                           | Ok (2)                       | Ok (2)                       |
| Horseback riding<br><b>Stay out of barns full of hay</b>                                                                                                                                                                                                                                                                                                    | No                           | Ok                               | Ok                           | Ok                           |
| Cats/dogs<br>Do not sleep, feed, bathe, or groom pets                                                                                                                                                                                                                                                                                                       | Ok                           | Ok                               | Ok                           | Ok                           |
| New pets in patient's household                                                                                                                                                                                                                                                                                                                             | No                           | No                               | No                           | No                           |
| Cleaning feces, litter boxes, utensils, cages, and tanks                                                                                                                                                                                                                                                                                                    | No                           | No                               | No                           | No                           |
| Domestic birds (parakeets, parrots, others)<br><b>Not if you have respiratory problems</b>                                                                                                                                                                                                                                                                  | No                           | Ok                               | Ok                           | Ok                           |
| Poultry and wild birds (pigeons, baby chicks, chickens, ducks, geese, and other wild birds)                                                                                                                                                                                                                                                                 | No                           | No                               | No                           | No                           |

| <b>Other activities</b>                                                                                 |    |               |               |               |
|---------------------------------------------------------------------------------------------------------|----|---------------|---------------|---------------|
| Golfing <b>(2)</b><br>Sun protection required; without venous catheter device                           | No | Ok            | Ok            | Ok            |
| Spectator events and crowds <b>(3)</b><br><b>No hand shaking</b>                                        | No | Ok <b>(3)</b> | Ok <b>(3)</b> | Ok <b>(3)</b> |
| Sexual activity                                                                                         | Ok | Ok            | Ok            | Ok            |
| Working with mechanical equipment (oil changes, working on cars and engines)                            | Ok | Ok            | Ok            | Ok            |
| Camping and hiking                                                                                      | Ok | Ok            | Ok            | Ok            |
| Down comforters (with cover)                                                                            | Ok | Ok            | Ok            | Ok            |
| School                                                                                                  | No | No            | No            | Ok            |
| Hot tubs<br>Avoid all public hot tubs <b>(6)</b>                                                        | No | Ok <b>(1)</b> | No            | No            |
| Swimming <b>(1)</b><br>Without venous catheter device, avoid head submersion and diving, use sun screen | No | Ok <b>(1)</b> | No            | Ok <b>(1)</b> |
| Gardening (digging in soil); mowing the lawn; raking leaves                                             | No | No            | No            | No            |
| Having plants in the home<br>Do not handle <b>(4)</b>                                                   | Ok | Ok            | Ok            | Ok            |
| Making/kneading yeast breads <b>(5)</b>                                                                 | No | Ok            | Ok            | Ok            |
| Carpenter work                                                                                          | No | No            | No            | No            |
| Occasional woodworking (sawdust)                                                                        | No | Ok            | Ok            | Ok            |

**Key:**

- (1)** No swimming if venous access device still in place (i.e., catheter) or patient history of sinusitis. Swim in chlorinated and well-maintained pools. Uncertain water conditions of lakes, rivers and the ocean for swimming are Ok if water is tested routinely for safety by local state and health departments; avoid small bodies of standing water (lakes and ponds). Swimming in pools used by non-toilet trained babies and children not recommended. Water aerobics Ok.
- (2)** Shooting rifles/shotguns & golfing is not recommended if venous access device still in place (such as a catheter).
- (3)** Recommend caution and an understanding of the risk involved when participating in public events or going to locations with large crowds.
- (4)** Real Christmas trees: in the water reservoir of the tree stand, use water solution of 1-part chlorine solution (Clorox®) in 10-parts water.
- (5)** Wash hands thoroughly with soap and water after kneading dough.
- (6)** Avoid all public hot tubs.



## Chapter 5 – Appendix





## Overview

The Fred Hutch, UW Medicine, and Seattle Children's have integrated their adult and pediatric oncology-related patient care services into a separate, jointly governed Seattle Cancer Care Alliance (SCCA). SCCA creates a highly integrated approach to cancer research and treatment. SCCA does not discriminate against any patient or patient's family member on the basis of race, color, religion, creed, national origin, sex, age, disability, marital or veteran status, sexual orientation, or gender identity. If you feel you experienced discrimination as a patient at SCCA, please contact SCCA Patient Relations at (206) 606-1056.

## SCCA purpose and principles

Seattle Cancer Care Alliance was formed to:

- Provide state-of-the art, patient-focused cancer care.
- Support the conduct of cancer clinical research and education.
- Enhance access to improved cancer interventions and advance the standard of care, regionally and beyond.
- Collaboration across the care delivery system.

## Inpatient services

Pediatric inpatients receive care at Seattle Children's, and adult inpatient services are provided at the University of Washington Medical Center (UWMC).

## Outpatient services

Outpatient services for Seattle Cancer Care Alliance are located at the SCCA clinic at 825 Eastlake Avenue East. If you have any questions regarding SCCA, feel free to ask your doctor or nurse.

## SCCA patient rights and responsibilities

SCCA respects the rights of all our patients equally and individually.

Seattle Cancer Care Alliance (Fred Hutchinson Cancer Research Center, UW Medicine, and Seattle Children's) was formed to provide state-of the-art, patient-focused cancer care, support the conduct of cancer clinical research and education, enhance access to improved cancer interventions, and advance the standard of cancer care, regionally and beyond. SCCA staff is committed to work as a team that includes you, as a patient, and your family members. SCCA respects the rights of all our patients equally and individually. SCCA does not discriminate against any patient or patient's family member on the basis of race, color, religion, creed, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity. If you feel you experienced discrimination as a patient at SCCA, please contact SCCA Patient Relations at (206) 606-1056.

## Patient rights

As a patient at Seattle Cancer Care Alliance you have the right to:

- Reasonable access to medical care within the capability of our mission, purpose, and principles, and in compliance with the appropriate laws and regulations;
- Medical care guided by the best medical practice;
- Confidentiality regarding your care and medical records;
- Understand how SCCA uses and discloses your health information ("Notice of Privacy Practices");
- Access your medical records (upon request) and an explanation of this information as necessary, except when doing so is restricted by law;

- Receive information in a manner that you can understand;
- Access interpreter services if you are non-English speaking or with vision, speech, hearing or cognitive impairment;
- Voluntary participation in all medical research studies;
- Care that is respectful of your cultural, psychosocial, and spiritual preferences;
- Care that supports privacy, personal dignity, and individual needs;
- Delivery of care that is free from mental, physical, sexual, or verbal abuse, neglect, or exploitation;
- Security and protection of your physical person and rights;
- Priority of medical needs over the objectives of any research study;
- Participate and make informed decisions in all aspects of your care;
- Open discussions about your care;
- Refuse treatment or services to the extent permitted by law, and be informed of the potential consequences of such an action;
- Treatment that does not prolong suffering, if your medical condition reaches a point where recovery is not realistically possible;
- End-of-life care that maximizes comfort, dignity, and quality of life as defined by you and your family;
- Appropriate assessment and management of pain;
- Be informed of options for ongoing medical care if the SCCA cannot meet the request or need for care, treatment or services (including discharge or transfer);
- Inspect and clarify your billing statements.

## **Patient responsibilities**

As a patient at SCCA, you share in the responsibility for your care. You have the responsibility to:

- Participate in decisions involving your care;
- Provide complete information about your health, symptoms, and medications;
- Ask your provider questions when you do not understand the planned treatment, care, or what is expected of you;
- Follow the treatment plan, which you and your provider have agreed upon;
- Keep appointments or let us know if you cannot make them;
- Take responsibility for the outcomes if you do not follow the treatment plan;
- Be considerate of the rights of other patients, personnel, and property;
- Follow SCCA rules and regulations;
- Provide accurate and timely information about sources of payment and your ability to meet financial obligations;
- Promptly meet any financial obligation agreed to with the SCCA;
- Let your providers know if you have concerns or complaints about any aspect of your care. SCCA encourages you, the patient, to talk with your healthcare team initially. Your nurse or social worker can be an advocate for you. If this course of action does not meet your needs we encourage you to speak with Patient Relations at (206) 606-1056. You may also make complaints to the Washington State Department of Health at 1-800-633-6828 or to the Joint Commission by calling 1-800-994-6610 or online at [www.jointcomission.org](http://www.jointcomission.org), or by e-mailing your concerns to [complaint@jointcomission.org](mailto:complaint@jointcomission.org). Medicare and Medicaid patients may also make complaints to Livanta LLC BFCC-QIO Program, 9090 Junction Drive, Suite 10, Annapolis Junction, MD 20701. Phone: 1 (877) 588-1123, fax (appeals): 1 (855) 694-2929, fax (all other types): 1 (844) 420-6672

## **Advance directives**

If you are an adult (at least 18 years of age and have the capacity to make health care decisions) you have the right to make your wishes known about the extent of treatment you would desire if you became unable to communicate those wishes. This communication is called an advance directive. Two commonly used advance directives are:

- A health care directive (living will), in which you communicate orally or in writing the specific treatment desired if you later cannot communicate these wishes.
- A durable power of attorney for health care, in which you designate another person to make decisions about your health care if you become unable to do so.

Social work staff are available to assist you with advance directives. SCCA will respect the intent of your directives to the extent permitted by law and SCCA policy.

## **Conflict resolution**

- Investigate any wrongful actions against your rights;
- Address concerns regarding patients' rights. SCCA encourages you, the patient, to talk with your health care team initially. If this course of action does not meet your needs, we encourage you to speak with Patient Relations at (206) 606-1056.

## **Personal valuables**

SCCA (including Fred Hutch, UWMC, and Seattle Children's) is not responsible for any loss or damage to your personal property including money, jewelry, watches, or other items of value. We strongly recommend that you not bring any of these items with you when you are being treated at SCCA.

## **Weapons and illegal substances**

Weapons and illegal substances are not allowed on SCCA property (including Fred Hutch, UWMC, Seattle Children's, Pete Gross House, and SCCA House). To report or request assistance in handling a suspected case or actual observed violation, contact our 24/7 security control room. The existence of a concealed weapons permit does not exempt a person from this policy. Please secure weapons before entering SCCA and its properties.

## Maps and directions

### To SCCA from I-5 north or south:

1. Take exit 167 Seattle Center/Mercer St.
2. Move to the far right lane and turn right at Fairview Ave. N.
3. Turn right at Aloha St and go 2 blocks.
4. SCCA will be on the right. Visitor parking for SCCA is beneath the building.

### To Seattle Children's from SCCA:

1. Travel north on Fairview Ave N or Eastlake Ave E (street becomes Eastlake Ave E).
2. Cross the University Bridge.
3. Continue north on 11th Ave NE.
4. Turn right at 45th Ave NE.
5. Turn left at Sand Point Way NE.
6. Follow signs for Seattle Children's Hospital.

### To UW Medical Center from SCCA:

1. Travel north on Fairview Ave N or Eastlake Ave E (street becomes Eastlake Ave E).
2. Cross the University Bridge.
3. Turn right at NE Campus Pkwy.
4. Turn right at Brooklyn Ave NE.
5. Turn left at NE Pacific St.



**To UWMC Surgical Pavilion:**

On Pacific Street, turn left at turning lane toward the Surgical Pavilion. Veer left into the Pavilion parking garage. Take garage elevator up to third floor (garage height restriction is 6' 8").

**To UWMC 8SE:**

From main entrance, follow signs for the "Cascade Elevators". Take elevators to 8<sup>th</sup> floor (8SE). Turn right from elevators and check in at the 8SE Reception Desk (parking can be validated here).

**To UWMC Triangle Garage:**

Access from NE Pacific Place off of Pacific Street, across the street from the Medical Center via a pedestrian tunnel under NE Pacific (garage height restriction is 6' 8")

**Addresses:****SCCA clinic**

825 Eastlake Avenue East

Seattle, WA 98109

(206) 606-7222

Parking at SCCA is \$4.00 with validation

**Seattle Children's Hospital**

4800 Sandpoint Way NE

Seattle, WA 98105

(206) 987-2000

**UWMC**

1959 NE Pacific St.

Seattle, WA 98195

(206) 598-3000

SCCA and the University of Washington Medical Center Garages (Surgery Pavilion and Triangle) offer same day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment and it will be honored.



## Charts and records

### Axillary (under the arm) temperature conversion chart

| °F    | °C   | What to do:                                                                                                                                   |
|-------|------|-----------------------------------------------------------------------------------------------------------------------------------------------|
| 96.8  | 36.0 | This is "normal" temperature range.<br>CALL DOCTOR for shaking chills.                                                                        |
| 97.8  | 36.6 |                                                                                                                                               |
| 98.0  | 36.7 |                                                                                                                                               |
| 98.2  | 36.8 |                                                                                                                                               |
| 98.4  | 36.9 | Do not take Tylenol®.<br>Re-check in 30 to 60 minutes for a temperature in this range taken under the arm.<br>CALL DOCTOR for shaking chills. |
| 98.6  | 37.0 |                                                                                                                                               |
| 98.8  | 37.1 |                                                                                                                                               |
| 99.0  | 37.2 |                                                                                                                                               |
| 99.2  | 37.3 | CALL DOCTOR for a temperature of 37.5 to 37.7° C (99.5 to 99.9°F)<br>taken under the arm, that continues for one hour.                        |
| 99.4  | 37.4 |                                                                                                                                               |
| 99.6  | 37.6 |                                                                                                                                               |
| 99.8  | 37.7 |                                                                                                                                               |
| 100.0 | 37.8 | CALL DOCTOR for a temperature greater than or equal to 37.8°C (100° F) taken<br>under the arm.                                                |
| 100.2 | 37.9 |                                                                                                                                               |
| 100.3 | 37.9 |                                                                                                                                               |
| 100.4 | 38.0 |                                                                                                                                               |
| 100.6 | 38.1 |                                                                                                                                               |
| 100.8 | 38.2 |                                                                                                                                               |
| 101.0 | 38.3 |                                                                                                                                               |
| 101.2 | 38.4 |                                                                                                                                               |
| 101.4 | 38.6 |                                                                                                                                               |
| 101.6 | 38.7 |                                                                                                                                               |
| 101.8 | 38.8 |                                                                                                                                               |
| 102.0 | 38.9 |                                                                                                                                               |
| 102.2 | 39.0 |                                                                                                                                               |
| 102.4 | 39.1 |                                                                                                                                               |
| 102.6 | 39.2 |                                                                                                                                               |
| 102.8 | 39.3 |                                                                                                                                               |
| 103.0 | 39.4 |                                                                                                                                               |
| 103.2 | 39.6 |                                                                                                                                               |
| 103.4 | 39.7 |                                                                                                                                               |
| 103.6 | 39.8 |                                                                                                                                               |
| 103.8 | 39.9 |                                                                                                                                               |
| 104.0 | 40.0 |                                                                                                                                               |
| 104.2 | 40.1 |                                                                                                                                               |
| 104.4 | 40.2 |                                                                                                                                               |
| 104.6 | 40.3 |                                                                                                                                               |

## Oral (mouth) temperature conversion chart

| °F    | °C   | What to do:                                                                                                                                         |
|-------|------|-----------------------------------------------------------------------------------------------------------------------------------------------------|
| 96.8  | 36.0 | This is “normal” temperature range. CALL DOCTOR for shaking chills.                                                                                 |
| 97.8  | 36.6 |                                                                                                                                                     |
| 98.0  | 36.7 |                                                                                                                                                     |
| 98.2  | 36.8 |                                                                                                                                                     |
| 98.4  | 36.9 |                                                                                                                                                     |
| 98.6  | 37.0 |                                                                                                                                                     |
| 98.8  | 37.1 |                                                                                                                                                     |
| 99.0  | 37.2 |                                                                                                                                                     |
| 99.2  | 37.3 | Do not take Tylenol®. Re-check in 30 to 60 minutes for a temperature in this range taken by mouth or under the arm. CALL DOCTOR for shaking chills. |
| 99.4  | 37.4 |                                                                                                                                                     |
| 99.6  | 37.6 |                                                                                                                                                     |
| 99.8  | 37.7 |                                                                                                                                                     |
| 100.0 | 37.8 |                                                                                                                                                     |
| 100.2 | 37.9 | CALL DOCTOR for a temperature of 38.0° to 38.2 C° (100.4°F to 100.8° F), taken by mouth, that continues for one hour.                               |
| 100.3 | 37.9 |                                                                                                                                                     |
| 100.4 | 38.0 | CALL DOCTOR for a temperature greater than or equal to 38.3° C or 100.9° F.                                                                         |
| 100.6 | 38.1 |                                                                                                                                                     |
| 100.8 | 38.2 |                                                                                                                                                     |
| 101.0 | 38.3 |                                                                                                                                                     |
| 101.2 | 38.4 |                                                                                                                                                     |
| 101.4 | 38.6 |                                                                                                                                                     |
| 101.6 | 38.7 |                                                                                                                                                     |
| 101.8 | 38.8 |                                                                                                                                                     |
| 102.0 | 38.9 |                                                                                                                                                     |
| 102.2 | 39.0 |                                                                                                                                                     |
| 102.4 | 39.1 |                                                                                                                                                     |
| 102.6 | 39.2 |                                                                                                                                                     |
| 102.8 | 39.3 |                                                                                                                                                     |
| 103.0 | 39.4 |                                                                                                                                                     |
| 103.2 | 39.6 |                                                                                                                                                     |
| 103.4 | 39.7 |                                                                                                                                                     |
| 103.6 | 39.8 |                                                                                                                                                     |
| 103.8 | 39.9 |                                                                                                                                                     |
| 104.0 | 40.0 |                                                                                                                                                     |
| 104.2 | 40.1 |                                                                                                                                                     |
| 104.4 | 40.2 |                                                                                                                                                     |
| 104.6 | 40.3 |                                                                                                                                                     |

## Blood counts

Day \_\_\_\_\_

Date \_\_\_\_\_

|               |            |  |  |  |  |  |  |
|---------------|------------|--|--|--|--|--|--|
| WBC           | 4 - 10     |  |  |  |  |  |  |
| ANC           | 3.2 - 4    |  |  |  |  |  |  |
| Polys         | 2 - 7.5    |  |  |  |  |  |  |
| Bands         | 0 - 1      |  |  |  |  |  |  |
| Lymphs        | 1 - 4.5    |  |  |  |  |  |  |
| Monos         | 0 - 1.4    |  |  |  |  |  |  |
| Eophils       |            |  |  |  |  |  |  |
| Basophil      | 0 - 0.3    |  |  |  |  |  |  |
| Metamyelocyte | 0          |  |  |  |  |  |  |
| Myelocyte     | 0          |  |  |  |  |  |  |
| Platelet      | 150 - 400  |  |  |  |  |  |  |
| SGOT          | <50 / 78   |  |  |  |  |  |  |
| Creatinine    | 0.7 - 1.5  |  |  |  |  |  |  |
| BUN           | 4 - 22     |  |  |  |  |  |  |
| Bilirubin     | <1.2 / 0.3 |  |  |  |  |  |  |
| Cyclosporine  | 300-1200   |  |  |  |  |  |  |

|                 |           |  |  |  |  |  |  |
|-----------------|-----------|--|--|--|--|--|--|
| RBC             | 4 - 5.3   |  |  |  |  |  |  |
| HGB             | 12 - 15   |  |  |  |  |  |  |
| HCT             | 36 - 45   |  |  |  |  |  |  |
| MCV             | 81 - 100  |  |  |  |  |  |  |
| MCH             | 27 - 35   |  |  |  |  |  |  |
| MCHC            | 32 - 37   |  |  |  |  |  |  |
| RDW             | 0 - 15.1  |  |  |  |  |  |  |
| Magnesium       | 1.5 - 2   |  |  |  |  |  |  |
| Sodium          | 136 - 145 |  |  |  |  |  |  |
| Potassium       | 3.5 - 5.5 |  |  |  |  |  |  |
| Chloride        | 95 - 110  |  |  |  |  |  |  |
| CO <sub>2</sub> | 23 - 31   |  |  |  |  |  |  |
| Glucose         | 60 - 110  |  |  |  |  |  |  |
|                 |           |  |  |  |  |  |  |
|                 |           |  |  |  |  |  |  |
|                 |           |  |  |  |  |  |  |

## Daily food intake sheet

[illegible]

## Bowel movement record

Please answer these questions at the end of the day.

Date \_\_\_\_\_

- How many bowel movements (stools) did you have today? \_\_\_\_\_
- How many times did you vomit today? \_\_\_\_\_

Please circle the number which best depicts your bowel movements today.

1. Watery
2. Liquid, creamy
3. Very loose, mushy, semi-liquid
4. Loose, soft
5. Formed with some liquid
6. Soft, formed
7. Normal, formed
8. Hard
9. Hard, dry

